CAREGIVER SATISFACTION: THE POSITIVES AND NEGATIVES OF CARING FOR INDIVIDUALS WITH DEMENTIA OR INTELLECTUAL DISABILITIES

By

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I declare that I am the sole author of this thesis and the work contained herein is my own. This thesis, or any part of it, has not been submitted for any other degree or professional qualification.

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ABSTRACT

Introduction: Within a context of increasing prevalence of both dementia and intellectual disabilities, the effects of these disorders on caregiver well-being is a pertinent topic of research. Yet caregiver satisfaction, a common experience within caregiving has been widely neglected in the literature to date. This study therefore aimed to assess levels of satisfaction between caregivers of individuals with dementia and caregivers of individuals with intellectual disabilities. In addition caregiver burden, caregiver wellbeing and care-recipient difficulties were also assessed.

Method: A cross-sectional independent groups design was used to assess differences between caregivers of individuals with dementia and carers of individuals with intellectual disabilities. Measures of caregiver satisfaction, caregiver burden, care-recipient difficulties and caregiver well-being were used.

Results: Caregiver satisfaction was found to be greater in carers of individuals with intellectual disabilities. There were no significant differences found in levels of caregiver burden, care-recipient difficulties or caregiver well-being between the two groups of carers. No effect of gender on caregiver satisfaction was found, however caregiver satisfaction was found to be related to kin relationship.

Discussion: The finding that caregiver satisfaction differs between different groups of caregivers may help resources to be allocated to those groups who are most in need. Limitations of this study, including a small sample size may have affected the results obtained and directions for future research, including a focus on more longitudinal studies that take into account care-recipient views are laid out.

CHAPTER 1: INTRODUCTION

Within a context of increasing prevalence of both dementia (Dementia UK, 2007) and intellectual disabilities (McGrother *et al*, 2001) caregiving for individuals with dementia and intellectual disability is set to remain a pertinent topic for research. This chapter aims to contextualise caregiving within the wider demographic and political context, outlining socio-political influences, which may affect carers and caregiver research. Caregiver characteristics will be discussed in terms of those factors common to the entire population of caregivers, and those that are specific to carers of individuals with dementia and intellectual disability respectively.

Individuals caring for people with dementia and intellectual disability may share common experiences, but also face unique challenges (Lundh, 1999; Whittick, 1988). The similarities and differences between different groups of carers will be highlighted in relation to past research. Comparisons of caregivers will be made both to non-caregiver populations and between individual caregiver groups in order to identify factors specific to caregiving experiences.

In order to explore more fully caregivers' experiences of satisfaction and burden, outcomes for these factors will be considered separately. Factors influencing the experience of positive (satisfaction) and negative (burden) outcomes when caring for individuals with dementia and intellectual disability will be discussed, once more exploring any similarities and differences between these populations. Due to limited

research in the area of caregiver satisfaction, particular emphasis will be placed on this. Finally research aims and hypotheses will be discussed.

1.1 The Demographic Context

The world's population is set to increase by 2.5 billion to 9.2 billion by 2050 (UN, 2006). It is estimated that by July 2007 the population of the world will be 6.7 billion. However this increase will be as a result of a rise in the number of people in developing countries. In contrast, the number of people living in more developed countries will remain stable at 1.2 billion (UN, 2006). Indeed, were it not for migration, these countries would see a decline in their populations. The UK is among those countries predicted to be major net receivers of international immigrants, estimated to obtain around 130,000 migrants per year.

Mortality within the developed world is low and continues to decline. Average life expectancy within the UK has risen from 58 years and 62 years for males and females respectively in 1931, to 75 years for males and 80 years for females in 2000 (Help the Aged, 2000). In addition, life expectancy in some developing countries, especially those not affected by the HIV/AIDS epidemic is beginning to increase.

There has also been widespread decline in fertility rates within developed countries. It is predicted that fertility rates will continue to decline within less developed countries and remain relatively stable within more developed parts of the world. Since 1995 fertility

rates have been at below-replacement levels in the majority of developed countries, including the UK and this pattern is set to continue.

Increasing longevity, together with decreasing fertility has resulted in widespread population ageing in developed countries around the world. In these parts of the world, the number of individuals aged 60 years or over is expected to almost double from 245 million in 2005 to 406 million by 2050 (UN, 2006). The number of individuals under 60 years will most probably decline, and it is estimated that by 2050 there is likely to be twice as many older people in developed countries as there are children (UN, 2006). The median age of the European population is currently 39 years. This is due to rise to 47 years by 2050 (UN, 2006).

Although the number of older individuals is increasing, most population growth can be seen in the number of people in the oldest age groups. Therefore, whilst the number of people aged 60 or over is set to triple, those aged 80 or over are set to increase by as much as five fold (UN, 2006).

Hence it is increasingly common for people, in developed countries at least, to survive into old age (Zarit & Edwards, 1996). Although many of these older individuals will be independent and able to care for themselves, there will be a proportion that requires assistance. As longevity increases and survival into old age becomes more prevalent then more people, especially those in the 'oldest old' age bracket, may require assistance in order to remain in their own home (Nolan & Lundh, 1999).

It is estimated that there are nearly 18 million people with dementia in the world (World Alzheimer's Day Bulletin, 2005). As a result of increased life expectancy, and enhanced detection of Alzheimer's disease (Prigerson, 2003), the most common form of dementia, this is expected to increase to 34 million by 2025 (World Alzheimer's Day Bulletin, 2005). Within the UK, the number of people with dementia is expected to increase by 154 per cent to over 1,700,000 by 2051 (Dementia UK). In addition to increases in life expectancy, advances in medical treatment have also resulted in more individuals, including those with disabilities and intellectual disabilities, living longer. Both individuals with intellectual disabilities and those with dementia often rely on family members, where available, and where not, on statutory services.

Due to the increase in the number of people potentially requiring care, the need to increase knowledge about the impact on caregivers is a very pertinent topic at this time. Focusing on the needs and experiences of informal carers is an important issue not only for carers and those they support, but also for society as a whole. After all, for those individuals who have no access to informal care, or indeed for whom care breaks down due to caregiver burden, help will be required from the state. The increasing numbers of individuals with dementia and with intellectual disabilities, resulting in increasing numbers of carers for these two groups, requires more attention. Looking at the positive and negative experiences of caregivers for both individuals with dementia and intellectual disabilities can help to provide valuable information that can inform interventions and perhaps help to maintain informal caregiving relationships.

1.2 The Political Context

The UK government has recognised the importance of informal care for more than twenty years (Kuipers & Bebbington, 2005) with information being collected every five years since 1985 regarding the extent of caring using the General Household Survey (Office of National Statistics). Since 1995 and the Carer's Recognition and Services Act, carers have had the right to request an assessment of their needs. Known as the Carers Act, this policy gave carers the right to an assessment by their local authority of their ability to care and to continue to care. There was an underlying expectation that those carers, who local authorities deemed to provide regular and substantial care, would be offered these assessments as a matter of course (Robinson & Williams, 2002). However it was left up to these authorities to determine what constituted regular and substantial care (Sneddon & Robinson, 2001) and this led to difficulties with interpretation of the Act (Carers National Association, 1997b). Evidence also shows that carers' knowledge of this legislation is minimal and that very few separate assessments are completed (Carers National Association, 1997a).

Sneddon and Robinson (2001) assessed the experiences of carers for people with dementia in relation to the Act. They found that they had limited knowledge of the Act, which was having a minimal impact with carers. A year later Robinson and Williams (2002) looked at the experiences of carers of individuals with intellectual disabilities who had received an assessment of their needs between 1997 and 1999 in the Southwest of England. They concluded that, once again, the Act was not widely used nor understood by this group of carers. Many parents of individuals with intellectual

disabilities, especially those with younger children, were uneasy about calling themselves carers, and see caregiving duties as natural parental functions. It is therefore possible that this group of carers may question the relevance of these assessments to their situation, providing one reason for the limited access to carers' assessments. However throughout their study Robinson and Williams (2002) also found confusion regarding the purpose of a carers' assessment or cynicism regarding its value. Many carers were unaware the assessment was to look at their needs and not at the needs of their relative with intellectual disabilities. It was also found that, due to limited contact with social services, many carers were not routinely being offered an assessment. Therefore the Carers Act failed to meet the needs of the majority of families caring for someone with an intellectual disability within this study (Robinson & Williams, 2002).

The National Strategy for Carers (1999) pledged to provide caregivers with better access to information, care and support (Orrell *et al*, 2006), and the role of informal carers was highlighted and portrayed as one of the most valuable roles within society (Nolan, 1999). A number of factors were identified as potentially having a positive impact on caregivers' well-being including respite from caring, greater social support, access to reliable and satisfactory services and a recognition of their role and contribution by others (Nolan, 1999). In order to achieve this £140 million of funding was provided between 1999 and 2002. This signalled a change in emphasis, with yet more of a focus being put on carers and not the care-recipient. Although aimed to support those individuals who choose to become carers and to provide equitable support throughout the UK (Lundh, 1999), it has been found that discrepancy still exists in the levels of

support provided for carers. For example Orrell *et al* (2006) surveyed over five thousand carers across seventy areas in England and found that access to support ranged from 22 per cent to 91 per cent.

In 2000 the British Government launched the Work-Life Balance Campaign (Department for Education and Employment, 2000), which aimed to encourage employers to offer more flexible ways of working for employees. This sought to assist workers with other commitments such as caring responsibilities. Although flexible working practices within the UK are increasing, the number of companies offering this way of working remains low (Phillips, 1998).

The 2001 Census (ONS, 2001) contained a new question on caring for the first time. This aimed to provide information on the numbers of carers by area within the UK in addition to information on specific groups of carers including the number of young carers and carers from black and ethnic minority groups. Information obtained from this census in relation to Scotland will be discussed later in this chapter.

A number of recent policy documents in Scotland have highlighted both the contribution that carers make to society and the need to provide a service for these caregivers themselves. The Community Care and Health (Scotland) Treatment Act (2002) identified carers as partners in the provision of care, and as such as a group of individuals who require the specific allocation of resources to enable them to carry out their caregiving duties. Like previous strategies (National Strategy for Carers, 1999;

Carers Act, 1995) this Act states that NHS Trusts should develop carer information strategies and provide carers with needs assessments, and recommends that local authorities should involve carers when devising care packages.

The significance of carers in reducing emergency admissions, enabling discharge of patients and in supporting elderly, disabled or ill individuals was recognised in the 'Delivering for Health' policy document published by the Scottish Executive in 2005. Five principal recommendations for the NHS stemming from this report aim to raise the profile of carers' health issues, develop carer participation and provide adequate information and training to enable them to fulfil this role. These principles were as follows:

- make carers' health a public health issue
- implement fully NHS carer information strategies
- encourage carer participation and partnership involvement in planning
- develop and provide carer training
- build 'carer awareness' into professional training

In an atmosphere where treatment is moving away from the hospital and towards more community based care there is the potential for carers to play a pivotal role in the care of their relatives. Acts such as The Mental Health Care and Treatment (Scotland) Act (2003), and The Adults with Incapacity (Scotland) Act (2000), aim to assist carers in meeting these goals.

It has been argued that policies to date have largely ignored the positive aspects that carers can experience as a result of caring, overlooking the often reciprocal nature of caregiving (Henderson & Forbat, 2002). For example Henderson and Forbat (2002) suggest that the National Strategy for Carers portrays caregiving as stressful and as a curtailing experience. Lloyd (2000) points out that the way in which caregiving is described in policies is inadequate and fails to represent the complex nature of caregiving relationships. This uneasiness with the way caregiving is defined and explored in policies and strategies is mirrored within current caregiver research and will be explored further in later sections of this chapter.

1.3 Models of Caregiving

Bowlby (1969/1982) argued that attachment between two individuals had an evolutionary purpose and that caregiving essentially provided protection to vulnerable individuals within society. Attachment theorists have postulated that the actions of a dependent are determined by a behavioural control system and that a complimentary caregiving behavioural control system determines caregivers corresponding reactions. The caregiver is thought to react to the needs of the dependent, and the motivation for providing this care is seen simply as an act that ensures the survival of the species. Bowlby (1969/1982) argued that emotion could be seen as an outcome of the caregiving bond, however stated that it was not causal in caregiving. For example love results from the development of a bond whilst distress occurs after a bond has been broken.

However this runs the risk of trivializing many of the difficult choices that caregivers experience. Bell and Richard (2000) argue that attachment theory fails to explain why caregivers who have other responsibilities and access to limited resources choose to continue to care or indeed why care is mostly directed towards a specific dependent. They have developed a model of caregiving referred to as the connection theory of caregiving, which they feel takes account of the limitations evident within a pure attachment model of caregiving. Within their model caring is seen as the motivation of caregiving and caregiving is derived from a caregiver's feelings towards a particular dependent. It is this emotional feeling that ensures that caregiving endures. Unlike in the attachment theory, caregiving is seen as proactive rather than reactive. Bell and Richard (2000) argue that this helps to explain differing levels of caregiving. Rather than caregiving being turned on or off as is suggested happens in attachment theories, caregiving is seen as a process that can occur at a number of levels and can account for the variation seen between caregivers and differing caregiving experiences.

1.4 Caregiver Characteristics

The term 'carer' is a broad concept that covers a range of individuals that may be involved in the care of others. The concept of caregiver is hard to define, and yet this may have an enormous effect on studies being carried out in the area of caregiving. Caregivers have been described as "invisible providers" (Fengler & Goodrich, 1979) or as "hidden patients" (George & Gwyther, 1986). They can be identified on the basis of

how much time they spend with care-recipients, or indeed, how much assistance they provide with tasks, such as with instrumental tasks like managing money, household chores and transportation or personal tasks like helping with activities of daily living or supervising their relative (Zarit & Edwards, 1996).

Although formal or paid carers play an essential role in assisting both individuals with dementia and intellectual disabilities, it is the impact upon informal or unpaid carers which is the focus of this study. The characteristics of these caregivers will now be discussed.

1.4.1 General Caregiver Characteristics

It is estimated that there are around six million informal carers within the UK, 90 per cent of whom are family members and 50 per cent of whom are over the age of 75 (National Strategy for Carers, 1999). Caregiving has been found to often fall on the shoulders of one family member who takes responsibility for the caregiving role, and to primarily be a female role (Parker, 1985; Neal *et al*, 1997). For example in Britain fifty-eight per cent of carers are female (National Strategy for Carers, 1999). This is perhaps because the demands of caregiving may be more familiar to females who often have long term experience of providing personal care to others (Pinquart & Sorensen, 2007).

The way in which a caregiver comes to find him or herself in a caring role tends to be a consequence of their relationship with the care-recipient. Shanas *et al* (1968) called this process the 'principle of substitution', claiming that where present, a wife becomes the

primary caregiver; when a wife is unavailable, a daughter assumes the role; and so on until a family member, friend or neighbour is found who will undertake caring responsibilities. Following on from this theory, Cantor (1975) proposed that caregiving tends to follow a 'hierarchical compensatory' model, or in other words that, a carer will be the individual who is the closest and most accessible person to the care-recipient. As a result it is often a single individual who can be faced with the physical and emotional burdens of caregiving.

In a recent meta-analysis, Pinquart and Sorensen (2007) aimed to highlight those caregiver characteristics that were associated with poor health within carers. They found that severity of care-recipients' cognitive and behaviour difficulties, length of care-giving career, co-residence, and kin relationship, feelings of burden and depression, age, socio-economic status and informal support were all related to the presence of physical health difficulties among caregivers. In prior studies these researchers also established that female carers (Pinquart & Sorensen, 2006) and ethnic minority carers (Pinquart & Sorensen, 2005), have greater levels of physical health difficulties than either male or Caucasian caregivers. However due to the fact that non-significant results are less likely to be published, and that these meta-analyses reviewed articles from peer-reviewed journals it remains possible this study overestimated the actual impact of caregiver characteristics on caregiver well being. The use of convenience samples, who often attended specific services for carers, in the majority of studies reviewed may also mean that it was those caregivers who were experiencing most distress who took part in these studies. Once more this may exaggerate the associations found to affect caregiver well-

being. Due to cross-sectional methodologies being used in all but 12 (6.8 per cent) of these studies it is not possible to determine causality and say that these caregiver characteristics led to decreased well being in carers. More longitudinal designs would allow caregiver experiences to be tracked over time. Finally, although Pinquart & Sorensen (2005; 2006; 2007) included a number of variables within their meta-analyses, a lack of published material assessing care-givers pre-existing health difficulties meant that this potentially important influence was not included in their analysis. Despite these limitations, they found that increased caregiver demands affected caregivers who were older and those who were caring for individuals with dementia, thus highlighting these risk factors for clinicians.

Caregiver characteristics explored in the above meta-analyses, together with a few other potential influences will be considered in turn in more detail throughout this chapter. Zarit and Edwards (1996) suggest that kin relationship affects feelings of commitment and obligation and in turn how caregiving is experienced; therefore both the level of distress felt by carers and their ability to continue caring can be affected by this. The closer the kin relationship, the greater the likelihood that these factors will play a part. Perhaps due to closer bonds with the care-recipient, spousal caregivers can experience more pronounced distress with their caregiving role (Zarit & Whitlach, 1992). Feelings of commitment or obligation towards caring responsibilities may mean that these individuals do not access support.

It is unclear whether the differences found are due to kin relationship, gender differences or other extraneous factors. Caring for a spouse has been shown to be affected by the gender of the caregiver, the prior relationship experienced with the care-recipient and whether or not the marriage was a first marriage (Baek, 2005). The finding that a caregiving relationship is more likely to break down if individuals are not in their first marriage has obvious implications for a society where the divorce rate and re-marriage rates are rising.

Differences have been found in the level of experienced burden between male and female caregivers, with female carers often reporting greater levels of burden than their male counterparts. It is however important to consider other factors which have been found to differ between the sexes, and which may account for these differences. Navaie-Waliser *et al* (2002) found that within a large representative sample of caregivers, women tended to be older, to be primary caregivers, to have poor emotional health and to care for care-recipients with greater difficulties than their male counterparts. Female carers were also less likely to use respite than male carers. Therefore the fact that female carers more frequently take on a primary caregiving role, often resulting in intensive caregiving, and are less likely to seek support until they reach the limits of their abilities, may explain why they experience greater distress than male caregivers (Navaie-Waliser et al, 2002).

The gender difference found in caregiver well being may also be as a result of differing caregiving responsibilities. Stone *et al* (1987) report that female carers are more likely to

provide assistance with personal hygiene and household tasks, with their male counterparts being more likely to aid with instrumental tasks such as transportation, D.I.Y., and financial management.

Caregivers who share a close blood-role relationship with a care-recipient, are also likely to share closer residency with a care-recipient. Therefore whether or not a caregiver lives with an individual requiring support may be the most important factor in determining caregiver well-being. Around 1.9 million carers in the UK are estimated to care for someone within the same household (National Strategy for Carers, 1999). This is important as it has been found that carers within the UK are 25 per cent less likely to receive help from service providers if they live with a care-recipient (Scottish Household Survey, 2005). Residing with a care-recipient has been shown to be related to physical health difficulties such as sleep deprivation and reduced nutritional intake (Pinquart & Sorensen, 2007). Care-recipient residency has been affected greatly by migration patterns. Due to increased relocation with the UK, more and more individuals are now living apart from other family members. This can obviously affect the availability of carers and the likelihood that they will take on caring roles.

It has been suggested that the age of a caregiver can affect the level of perceived distress with their caregiving role. For example Pearlin and Schooler (1978) state that there are disparities in the way different age groups cope with their caregiving role. Younger carers are more likely to be self-denigrating than older carers, however they are also more likely to entertain a sense of mastery than their elderly counterparts. This may be

important in Britain as two-thirds of carers are aged 45 and over (General Household Survey, 1995; Office of National Statistics) (See Figure 1.1).

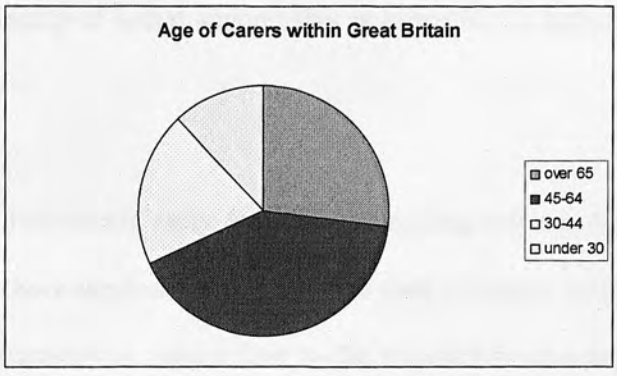

Figure 1.1: Carers by Age in Great Britain. Source: General Household Survey (1995)

Mastery has been found to be a protective factor against depression (Beck *et al*, 1979). Therefore if older caregivers are less likely to experience mastery (Pearlin & Schooler, 1978), they may be more susceptible to mental health difficulties such as depression as a result of their caregiving responsibilities.

Poulshock and Deimling (1984) found evidence that whether or not an elderly dependent remains in the community is also related to the amount of family support provided to the caregiver. Social support can often be very important for the supporter of an ill or disabled relative. Due to the extensive nature of caregiving, such as caring for an individual with dementia or an intellectual disability, many supporters can become isolated. However support is difficult to define, for example the involvement of other family members or friends in the care of a relative may be a source of both support and

conflict (MaloneBeach & Zarit, 1995). Thompson *et al* (1993) found that not all types of social support helped reduce caregiver burden. Support which focused on conversing about caring duties or the dependent was more corrosive. Therefore it may be the quality rather than the quantity of social support that is important in reducing distress among caregivers.

The nature of an individual's entry into their caregiving role has been found to be of importance and to have implications for how the path of caring will develop (López *et al*, 2005). The circumstances, which lead to the acquisition of a caregiving role, may influence an individual's experience of satisfaction in that role. For some carers entry into a caregiving role may occur gradually and for others it may occur after a crisis. Recent research has suggested that, rather than a "wear and tear" (Townsend *et al*, 1989) effect on the caregiver, that it is more likely that caregivers adapt to changing care demands (Suitor & Pillemer, 1994; Gaughler *et al*, 2007) and that caregivers often begin their caring responsibilities prior to the onset of obvious impairment. According to Frankl (1963), making the choice to become a carer can allow the caregiver to attribute meaning to their role, a factor that has been found to be important in those caregivers ss experience satisfaction (López *et al*, 2005). However, caregivers often report that they have not had much choice in their acceptance of a caregiving role; frequently being influenced by societal pressures (Sommers & Shields, 1987). It is likely that those individuals whose caregiving career coincides with abrupt transitions such as a medical diagnosis of their relative, experience greater distress and more negative outcomes such as guilt, role overload and depression (Gaughler *et al*, 2003).

Therefore there are a multitude of variables that may affect caregiver burden and satisfaction. It can be difficult to distinguish which aspects of caregiving affect experience. The researcher aims to distinguish which of the above factors may be related to the experience of satisfaction within caregivers of individuals with dementia and intellectual disabilities within an NHS Trust in Scotland.

1.4.2 The Growing Need for Carers in Scotland

It is estimated that there are approximately 480,000 unpaid carers in Scotland and that 13 per cent of the adult population in Scotland are carers (National Strategy for Carers, 1999). Of these, 115,000 people care full time, and together these carers contribute around £5.3 billion worth of care to the population of Scotland (Scotland's Carers Manifesto, 2007). When carers are forced to give up caring due to lack of support there is a high price to pay both in terms of replacing this lost care with formal services, and in terms of the detrimental effects on carers' own health.

The Scottish Household Survey estimated that 51 per cent of care by a co-resident carer is provided continuously, compared to a National estimate of 38 per cent (Scottish Household Survey, 2005). Given the fact that those carers who reside with care-recipients are less likely to receive support from formal services this would suggest there is potentially a high level of need within this vulnerable group in Scotland.

Within the NHS Trust where this study took place, 23 per cent of the population is estimated to have a long-term illness that limits their activities of daily living or work activities (Census, 2001). This is higher than the national average and suggests that within this area there are potentially a greater number of carers requiring support and assistance in order to carry out their caregiving responsibilities. The 2001 Census contained within it for the first time a question regarding caregiving duties; from this it is estimated that approximately 65,000 people within the NHS Trust which was the focus of this study, i.e. around 10 per cent of the population, are unpaid carers. Of these, 40 per cent care for between 20 to 50 plus hours a week. These carers will include those assisting individuals with dementia and intellectual disabilities.

1.5 Caregivers of Individuals with Dementia and Individuals with Intellectual disabilities

As the general characteristics found within carers have already been identified and the need for carers in Scotland, including the local area of investigation of this study, has been outlined, the specific characteristics of carers for individuals with dementia and intellectual disability will now be discussed.

1.5.1 Caregivers of Individuals with Dementia

The Alzheimer Association define dementia as:

> "The loss of intellectual functions (such as thinking, remembering, and reasoning) of sufficient severity to interfere with a person's daily functioning. Dementia is not a disease itself but rather a group of symptoms that may accompany certain diseases or

conditions. Symptoms may also include changes in personality, mood and behaviour." (Alzheimer's Disease Association; www.alz.org)

The Dementia UK (1997) report has suggested that around 1.1 per cent of the UK population are thought to have dementia, and that around 56,000 people in Scotland have dementia (Dementia UK, 1997). It is estimated that the financial cost of dementia to the UK economy is around £17 billion a year, with caregivers estimated to save the UK £6 billion per annum. The proportion of people with dementia doubles for every five-year age group; for example, although the prevalence rates for dementia in individuals aged 40-64 years is 1 in 400, for those aged 80 years or more, the prevalence rises to 1 in 6 individuals (Dementia UK, 2007). Despite early onset dementia being rare, it is estimated that around 15,000 younger people have dementia in the UK (Dementia UK, 2007). This is likely to be an underestimate as these figures are based on referrals to services only.

The type of relationship which a caregiver has with a care-recipient has been shown to affect the level of perceived burden and satisfaction reported by dementia carers. For example spouse caregivers have been shown to have increased levels of depression (Schulz *et al*, 1995; Gallagher-Thompson, 2006). Baikie (2002) looked at the nature of the marital relationship when one partner had received a diagnosis of dementia, and suggested that some of the negative consequences of caring may be due to reduced shared activities, loss of emotional support and a decline in the quality of verbal communication between a couple. In essence she argued that these changes may affect caregiver well being and their perception of marital satisfaction.

The quality of relationship that a caregiver and care-recipient shared prior to the onset of dementia is also crucial. For example Gilhooly and Sweeting (1994) assert that a good prior relationship has been found to be an important aspect of caregiver well-being and satisfaction, and also in predicting how long an individual will continue to care for a care-recipient; whereas López *et al* (2005) suggest greater caregiver satisfaction within those caring for individuals with dementia has been associated with better previous affectionate relationships. Perhaps this is due to increased feelings of commitment and decreased feelings of resentment, which may come with this type of bond. For example a low level of intimacy premorbidly is associated with both higher levels of burden and depression in dementia caregivers (Morris *et al*, 1988), and to a greater incidence of abuse within the caregiving relationship (Compton *et al*, 1997).

A caregiver's gender may also be important. It has been found that men, in general, tend to show lower levels of distress than women when caring for individuals with dementia (Gilleard *et al*, 1984), including early onset dementia (Takano, 2005), and that they report more positive aspects associated with caregiving than do women (Levesque *et al*, 1995). Possible reasons for differences in coping ability between the sexes have been offered by Gilligan (1982) and Gilhooly (1984). These include the fact that women are often more emotionally involved in their caregiving role; women are less likely to leave the care-recipient home alone, and therefore are less likely to get respite; women may be more likely to admit distress than their male counterparts and the physical tasks of caring may be more demanding for females. Gilligan (1982) further suggested that

woman place a greater emphasis on personal relationships, and have a greater "ethic of caring" than do men. However it has also been recognised that caring for an individual with dementia often coincides with a wish by many women to move away from child rearing and towards other personal opportunities and growth (Zarit *et al*, 1986). As such caregiving demands often conflict with female desires for increased autonomy (Fitting *et al*, 1986) and may therefore provide cause for greater dissatisfaction amongst female caregivers. Furthermore females tend to report a higher incidence of depression in the general population than males (Fitting *et al*, 1986) and this may account for the differences in distress levels between the sexes. It has also been suggested that although levels of depression within male caregivers are initially lower than female caregivers that they raise to a level comparable to females as care progresses. For example female carers tend to show high rates of depression earlier on in their caregiving career and this remains level over time; in comparison male carers' show increasing rates of depression over time (Schulz & Williamson, 1991).

Although some differences have been found between male and female caregivers in terms of the degree of distress or satisfaction experienced, it is important to remember that male caregivers are often under-represented in the caregiving literature. Many caregiving studies use small convenience samples and often fail to analyse data depending on gender (Houde, 2002). There is a need for more research using larger samples of male caregivers in order to evaluate the effects on both male and female caregivers. As more females are diagnosed with dementia, and as more males with less stereotypical role expectations come of age, it is likely that greater numbers of male

caregivers will be required to shoulder the burden of caring (Harris, 1993; Houde, 2002). It is therefore important that this group of carers not be neglected within the literature.

Migration has resulted in more people living away from close family members (Zarit & Edwards, 1996) and therefore fewer individuals are in a position to care for loved ones if they become unwell. This changing pattern of residency also has the potential to affect relationships within the family if an individual develops dementia. Gilhooly (1987) found that relationships between parent carers without dementia and their adult children can be damaged, with resentment developing, if the children fail to aid their parents in caregiving duties.

Residing with a care-recipient may also affect levels of burden among caregivers (Pinquart & Sorensen, 2007). Seventy per cent of people with Alzheimer's disease are cared for at home, with three-quarters of this care being provided by informal carers (Alzheimer's Association, 1996). Gaughler *et al* (2007) found that those caregivers of individuals with dementia who resided with a care-recipient often cared for a dependent that had greater cognitive and physical impairments and were more likely to have difficulty undertaking their own activities of daily living tasks. Therefore caregiving may have posed a greater challenge to these carers. However the authors of this study admit that other important factors, such as personality characteristics, self efficacy and support mechanisms were not measured in this sample of caregivers. All of these factors may also have affected levels of perceived burden amongst caregivers, whether they resided with a care-recipient or not.

Due to the fact that Alzheimer's disease is more common in older people, it is common for family caregivers to be elderly themselves and they may face additional challenges related to this, such as their own health difficulties (Prigerson, 2003). These additional stressors may result in older carers experiencing greater distress. However Fitting *et al* (1986) suggest that it is also possible that younger carers of individuals with dementia may feel more burdened by their caregiving role due to the fact it may be an unexpected responsibility at that stage in their lives.

The amount of support an informal caregiver receives either from other family members or from formal services can also affect their levels of burden (Pearlin *et al*, 1990) and depression (Wayte *et al*, 2004). Caregivers who report less burden tend to receive more family visits (Zarit *et al*, 1980) and are more satisfied with the help given (Gilhooly, 1984a). Heru and Ryan (2006) examined family functioning, burden, quality of life and reward in 38 caregivers of people with dementia at two time points (recruitment and one year follow-up). A correlation was found between poor family functioning and increased caregiver burden at initial recruitment phase, however no change in family functioning or caregiver burden was found at one year follow-up. This limits support for a 'wear and tear' theory of burden, where increased length of caregiving is thought to result in greater caregiver burden (Townsend *et al*, 1989). A high number of drop-outs though may mean that data was lost on those caregivers who experienced increased burden and poorer family functioning over the year long study.

Support may come in many different forms, and is likely to differ depending on the gender of the caregiver. Male caregivers for example have been found to rely more heavily on clergy for social support (Harris, 1993). Harris (1993) suggests that for many men, their wives are the main link to a social network of friends and support. Therefore when females develop dementia, and this resource is lost, male spouse caregivers must find alternative sources of support. In her study Harris (1993) also found that male caregivers were uncomfortable talking about many aspects of caregiving such as sex, companionship and caregiving duties such as maintaining personal hygiene of the care-recipient, in front of females. Perhaps gender specific services, which look at differing needs within male and female caregivers, are needed.

Researchers have suggested a number of different reasons for a link between social support and caregiver well-being. It may be the inability to do what one previously did that adds to the feelings of burden and stress within the caregiver (Gilhooly, 1987). It may also be that engaging in social activities is physiologically rewarding (Kiecolt-Glaser and Glaser, 1989) or a source of distraction (Gallagher-Thompson *et al*, 1989). Or it may be that those caregivers who experience more burden, feel less deserving of recreational activities, and are less likely to leave dependents, thus resulting in less uptake of social support (Thompson *et al*, 1993). Prigerson (2003) also points out that, unlike with other terminal illnesses, when individuals have late stage dementia their caregivers are unlikely to receive support from palliative care services which have been shown to reduce caregiver burden in other groups of carers.

The way in which caregivers enter their caring role is also important for dementia caregivers. For example López *et al* (2005) found greater reports of satisfaction amongst those carers whose role was not imposed on them. Gaughler *et al* (2003) also found that those dementia caregivers who had a less abrupt entry into their caregiving role reported greater levels of satisfaction and were also less likely to institutionalise their relatives. Those caregivers involved in assisting the care-recipient prior to diagnosis or recognition of dementia reported less role overload and depression over three years than those caregivers whose entry into caregiving was as a result of diagnosis or recognition of dementia in the care-recipient. The results of this study further contradict the 'wear and tear' theory (Townsend, 1989). Rather than caregiving causing increasing demands as time progresses, it appears that caregivers may adapt to their situation and develop effective coping styles which can be utilized after a diagnosis has been received. In contrast, individuals whose caregiving responsibilities began after diagnosis may have felt overwhelmed by their new role. It is also possible that diagnosis for this group occurred after some sort of crisis, suggesting a more rapid decline in abilities (Gaughler *et al*, 2003). Levels of guilt, role overload and depression fluctuated across these groups over the three year study period, making it difficult to draw firm conclusions about the link between burden and length of caregiving.

The length of time that carers have been in their caring role in addition to the amount of time spent caring each day may be important factors to consider when gauging caregiver satisfaction (Nolan *et al*, 1996). Individuals with dementia can live for an average of eight years and up to twenty years after receiving their initial diagnosis (Prigerson,

2003). Therefore caregiving can extend over long periods of time. Motenko (1989) did not find length of caregiving role to be important in determining distress; what was significant was the amount of disruption to the carer's life that caregiving had caused. In a four year longitudinal study Walker *et al* (1996) found that, contrary to the wear-and-tear hypothesis, the duration of caregiving had no effect on either initial caregiver satisfaction or in changes in satisfaction over time.

Caregivers of individuals who have dementia are faced with observing the gradual loss and decline of their loved one. Although Eagles *et al* (1987) found that the levels of stress within caregivers increased with increasing dementia severity, research studies have failed to consistently find an association between dementia severity and burden. Gilhooly and Sweeting (1994) point out that, due to the presentation of less difficult behaviour in the early stage of dementia and the requirement of more nursing type care in the later stages of dementia, that carers may find it less difficult to deal with individuals during these stages. It is therefore those caregivers looking after individuals with moderate levels of dementia that may feel most strain. It has been suggested that factors such as appraisals, coping and social support are more predictive of caregiver physical and mental well-being than severity of dementia in dependents (Goode *et al*, 1998). It is also possible that the failure to find an association between dementia severity and burden may in fact be due to the use of inappropriate measures of severity (Gilhooly, 1984; 1994).

1.5.2 Caregivers of Individuals with Intellectual disabilities

According to the American Association on Mental Retardation (1992) an individual must exhibit impairment in intellectual functioning and adaptive functioning before the age of 18 years (Emerson *et al*, 1998) in order to receive a diagnosis of an intellectual disability.

The prevalence of people with an intellectual disability within the UK has increased by around one per cent over the last 35 years (McGrother *et al*, 2001). Around 22,500 adults with intellectual disorder are known to live in Scotland (Scottish Executive, 2005), however as will be outlined below, this is likely to be an underestimate. 'The Same as You?' (2000) reviewed services for people with intellectual disabilities in Scotland and made 29 recommendations for improving inclusion within the wider population. This policy signalled a fundamental change in the direction of services for individuals with intellectual disabilities, and outlined a move towards community based care. Given the increase in the number of individuals with intellectual disabilities, and an increase in the number of individuals with intellectual disorders who are living in the family home there is an ongoing need for research into this group of carers.

It is estimated that around 20 people per 1,000 have a mild to moderate intellectual disability and 3 to 4 people in every 1,000 have a severe intellectual disability (Health Needs Assessment, 2004). Therefore as many as 120,000 people in Scotland may have an intellectual disability (Health Needs Assessment, 2004). The majority of these individuals will require help to remain in their own homes.

Similarly to carers of individuals with dementia, caregivers for those with an intellectual disability tend to be female, with a mother most typically shouldering the majority of caregiving duties (Parker, 1985). Researchers have raised concerns that women's shouldering of most caregiving duties may result in greater caregiver burden for mothers (Heller *et al*, 1997). Pahl and Quine (1987) found that less than one fifth of fathers helped with feeding, changing, toileting, dressing and washing, and getting up with their child during the night. In this same study siblings were found to provide even less support than husbands for these tasks. These findings fit with theories that it is the individual who is closest and most accessible to the individual requiring assistance who will take on the caregiving role. These theories (Shanas *et al*, 1968; Cantor, 1975) have been outlined in an earlier section of this chapter.

The reduced hospitalisation of individuals with intellectual disabilities has resulted in the majority of care taking place within the community and has had significant implications for caregiver research (Essex & Hong, 2005). Most parents of adults with intellectual disabilities continue to live with and care for their children well into later adulthood (Hong *et al*, 2001). McDermott *et al* (1997) compared caregiver burden and gratification in both caregivers who resided with an individual with intellectual disabilities and in carers whose relative lived out with the family home. No significant difference was found between these two groups in levels of burden and gratification, however overall levels of burden were high in both. Despite this, caution is required before drawing any firm conclusions from this study. Due to the cross-sectional methodology utilized it is

not possible to conclude whether those carers, caring for individuals who had been placed out with the family home, had higher levels of burden (or gratification) when the care recipient resided in the family home (McDermott *et al*, 1997). It may be the case that these caregivers had experienced a reduction in caregiver burden as a result of the care-recipient moving away from home. A longitudinal design following caregivers across their caregiving career could perhaps better determine if burden does in fact differ depending on the residency of the care-recipient.

It is estimated that up to 40 per cent of individuals with an intellectual disability who live at home have one or more carers aged 60 or over, and 10 per cent live with a sole carer over 70 years (Watson & Harker, 1993). This therefore represents a life-long commitment for many parents and sets them apart from other carers, such as individuals caring for people with dementia. In contrast to being suddenly catapulted into a new role, they have built up their role over their relative's lifetime (Robinson & Williams, 2002). These parents have to confront the reality that they face lifelong caring responsibilities, and the recognition that their child may face limitations in their ability to live independently can lead to feelings of loss and grief (Kim *et al*, 2003).

These carers will potentially face further challenges in their role as a carer as they age. They may face the unenviable dilemma of who will care for their children as they age (Bigby & Ozanne, 1999) or in the event of their death. This factor is one of the clearest differences in the experience of caregiving between caring for someone with intellectual disability or someone with dementia. As with dementia caregivers, they may face greater

difficulties in dealing with the physical demands of caring, and indeed may have physical health difficulties of their own which make these tasks harder (Kim *et al*, 2003). They may be faced with changes in roles and relationships due to divorce or widowhood (Kim *et al*, 2003), or with undertaking a multitude of caregiving demands as they age. For example they may be faced with caring for their child, as well as for other family members who may become frail and also require care (Seltzer *et al*, 1995).

As individuals with intellectual disabilities live longer, the rates of dementia in this population will also increase. Dementia is at least twice as prevalent in people with intellectual disabilities as in the general population (Turner & Moss, 1996), especially those with Down syndrome who are at particular risk of developing dementia. This is becoming an increasingly important issue for services, but more so for family caregivers, who will undertake the majority of this care.

Individuals with an intellectual disability and their carers who are not receiving services have been found to be considerably older than those who are in receipt of services (Finnegan *et al*, 2004). Those who received services also faced more severe physical disabilities (McConkey, 2005), while their carers were found to have higher levels of stress and poorer mental health (Finnegan *et al*, 2004).

A variety of characteristics therefore have the potential to influence the outcome of caring, both when caring for an individual with dementia and with intellectual disorders. Indeed a prominent feature of caregiver research is the great variability in outcomes and

experiences both between carers and within individual carers. The next section will attempt to account for some of this variability within the literature.

1.5.3 Variability in the Caregiving Experience

Caregiving is a unique and dynamic event. The diversity of response to care demands is a consistent conclusion within the literature (Gaughler *et al*, 2007). It has been suggested that this is due to differences in caregivers' interpretations of their role, and that caregiver appraisal is more related to perceived burden or satisfaction than to the caregiving tasks themselves in both dementia caregivers (Haley *et al*, 1987) and intellectual disability caregivers (Orr *et al*, 1991).

Caregiver appraisal may be positive, negative or neutral (Kinsella *et al*, 1998) and consists of a cognitive and affective appraisal regarding the stressor and coping self-efficacy (Lawton *et al*, 1989). Burden results when an individual perceives a discrepancy between the perceived stressor and their ability to cope with that stressor (Nolan *et al*, 1990).

Carer expectations have been shown to be related to levels of depression within dementia caregivers; those with unrealistic expectations have higher rates of depression (Coppel *et al*, 1985) and on the other hand those with lower expectations report lower depression (Saad *et al*, 1995). It has been found that appraisals related to loss of control, powerlessness and uncertainty regarding ability to continue to care are related to caregiver burden (Coppel *et al*, 1985; Morris *et al*, 1988). Mothers' appraisals regarding

having a child with an intellectual disability have been found to be related to their amount of adjustment and their level of reported stress (Quine & Pahl, 1991).

Being able to identify positive aspects of a situation, the so-called 'silver lining effect', has been acknowledged as a powerful cognitive coping strategy (Summers *et al*, 1989). Maintaining positive attitudes about a care-recipient can preserve commitment to caring and reduce perceived strain (Walker *et al*, 1992). Motenko (1989) found that those carers who perceived caregiving as providing reciprocity for past affection or as providing a nurturing role expressed greater satisfaction than those who appraised their role as a responsibility. These interpretations can provide a source of fulfilment and gratification when undertaking even the most stressful caregiving tasks. The ability to identify positive appraisals has been found to be important in buffering stress, both within dementia caregivers (Rapp & Chao, 2000) and those caring for individuals with an intellectual disability (Seltzer *et al*, 1995).

1.6 A comparison of Caregiving Experiences: Similarities and Differences in Caregiving

The caregiving literature will now be examined, focusing on comparisons of different caregiver groups, including caregivers of individuals with dementia and intellectual disabilities.

1.6.1 A comparison of Caregivers

Caregiving is considered to result in morbidity amongst carers; unsurprisingly caregivers have been found to fare worse than non-caregivers in terms of well-being and quality of life. Borg and Hallberg (2006) compared non-caregivers with informal caregivers who had frequent caring duties, and informal caregivers who had less frequent caring duties. Those caregivers who took part in frequent caring responsibilities were found to be older, more likely to be married and retired, and more likely to perform personal activities of daily living for the care-recipient. They exhibited slightly lower satisfaction, as measured by the Life Satisfaction Index (LSIZ) than both non caregivers and caregivers with less frequent caring duties. However a low response rate may have resulted in a selection bias which could have affected these results. In addition, this study looked at various groups of caregivers; therefore different results may be achieved when measuring specific caregiver groups such as those caring for individuals with dementia or those caring for individuals with intellectual disabilities.

It is well recognised that caring for a relative with dementia is very stressful and it has been suggested that caring for an individual with dementia is more stressful than caring for both individuals with other mental disorders (Gilhooly, 1987) and for individuals with physical health problems (Pinquart & Sorensen, 2003). Similarly, McKee *et al* (1992) found that dementia caregivers had higher General Health Questionnaire (GHQ) scores than those caring for elderly persons who had suffered a stroke, suggesting that caregivers within the dementia group had more health requirements. When compared to

supporters of the non-demented elderly, caregivers of individuals with dementia were found to have increased levels of stress (Eagles *et al*, 1987).

Eagles *et al* (1987) and Pinquart and Sorensen (2003) found that supporters of dementia relatives had significantly higher rates of distress than supporters of non-demented relatives. Despite this they have been found to access fewer services than other groups of caregivers (Birkel & Jones, 1989). It may therefore be that those caregivers who are most in need of support, are the least likely to access it.

1.6.2 A comparison of Caregivers of Individuals with Dementia and Intellectual disability

Caregivers of individuals with dementia and intellectual disabilities face differences in the timing of onset and the types of demands they will face. Intellectual disabilities are often identified at, or soon after, a child is born. Therefore carers, typically parents, begin caring responsibilities in their twenties or thirties (Kim *et al*, 2003). In contrast, carers of individuals with dementia can assume this role at a variety of life stages. Spouse caregivers may be a lot older when they first take on caregiving responsibilities. Seltzer *et al* (1995) argue that, due to the greater stability of disabilities over time and increased responsiveness from services to the needs of carers, that carers of individuals with intellectual disabilities experience a greater sense of mastery in dealing with caregiving tasks. Greater control over their caregiving experience may increase the likelihood that attempts to problem solve are successful, which may in turn reduce feelings of burden and depression (Kim *et al*, 2003).

In a study looking at the experiences of caregiving between carers of people with dementia and carers of people with an intellectual disability, Whittick (1988) used a postal survey to compare daughters caring for a parent with dementia, mothers caring for a child with an intellectual disability and mothers caring for an adult with an intellectual disability. Whittick (1988) found that despite elevated levels of emotional distress among all three of her comparison groups, that when these groups were compared to the general population, there was only a significant difference between the first two experimental groups and the general population. Therefore only daughter caregivers of parents with dementia and parent caregivers of children with intellectual disabilities had significantly greater distress than the general population. When comparing dementia caregivers with intellectual disability caregivers, Whittick (1988) found that daughters caring for a parent with dementia had significantly higher levels of distress than either mothers caring for adults with intellectual disabilities or mothers caring for children with intellectual disabilities. Elevated levels of distress (as measured by the 30 item General Health Questionnaire, Goldberg 1978) within daughter carers of parents with dementia may be explained by the fact that they may have had less time to adjust to their caregiving responsibilities, they may experience a greater change in their role compared to mothers of children or adults with intellectual disabilities who may see caregiving as an extension of their maternal role. However caregivers of individuals with intellectual disabilities had greater access to services and this may also account for the reduced levels of distress within this group. A response rate of 50 per cent also means that sampling bias may have affected the results.

When West *et al* (1984) surveyed the general public regarding their views of where care-recipients should be cared for, they expressed the view that most impaired people should be cared for within the community, except for people with dementia, whom they felt should either be placed in residential care or, if necessary, receive high levels of professional support in order to remain within the community. This may reflect a general perception amongst the public that caring for someone with dementia is more difficult than caring for other dependent groups (Whittick, 1988).

1.6.3 Differences between Caregivers of Individuals with Dementia and Intellectual disability

In a study looking at sources of satisfaction and burden amongst Swedish caregivers, Lundh (1999) found that being able to see small improvements in their disabled children, and helping them to reach their full potential provided parents with satisfaction. These factors were not seen to apply to dementia caregivers.

Potential reasons for differences between carers for those with dementia and those with intellectual disabilities are multifaceted and complex. Perhaps mothers with disabled children are more likely to undertake a caring role out of a sense of maternal duty (Whittick, 1988), with caregiving being an extension of natural responsibilities, whilst caregivers for people with dementia may begin caring out of a sense of obligation (Gilhooly, 1984a). Thus carers of people with intellectual disabilities may have taken on

their role for more positive reasons and this may lead to reduced feelings of burden in this group.

This difference in burden may also be due to the fact that mothers will have potentially had a greater amount of time in which to come to terms with their caregiving role, in addition to the fact that this role perhaps follows the more natural concept of a parent-child relationship. In contrast, daughters caring for a parent with dementia may experience role reversal and may also have found themselves thrust into this role relatively suddenly, perhaps at a time in their life when they were free from dependents and in possession of other non-caring aspirations (Whittick, 1988). Of course the progression of impairment in dementia compared to the relative stability within intellectual disabilities may be another factor which contributes to mothers caring for a disabled child/adult feeling less strain (Seltzer *et al*, 1995). In her study Whittick (1988) also found a difference in the amount of formal support offered to different groups of caregivers, with caregivers of individuals with dementia receiving less input from professionals than caregivers of individuals with intellectual disabilities.

1.6.4 Similarities between Caregivers of Individuals with Dementia and Intellectual disability

Nearly two thirds of a sample of 123 Swedish caregivers, including both carers of individuals with dementia and carers of individuals with intellectual disabilities, felt that caring for a loved one had brought them closer to the care-recipient; this was especially relevant for parents caring for children (Lundh, 1999).

The progressive nature of dementia and the magnitude of difficulties, although stable, within intellectual disabilities means that caregivers for both groups of individuals face many difficulties. Memory and behaviour problems have been shown to be an important factor in determining caregivers' feelings of burden and satisfaction (Rapp & Chao, 2000; Kramer, 1993). These problems are common in both dementia and intellectual disabilities.

1.7 Caregiver Burden: The Negative Aspects of Caring

This section will discuss the negative aspects of caregiving; outlining models of stress and types of coping which may affect the perception of stress within caregivers, and concluding with a comparison of carers of individuals with dementia and intellectual disabilities with regard to carer burden.

Caregiver Burden has been referred to as "the oppressive load borne by people providing direct care for the chronically ill" (Hunt, 2003). Two main types of burden have been identified (Pearlin *et al*, 1990); objective burden resulting from the care-recipients' illness (Jones, 1996) and subjective burden as a consequence of negative appraisals or feelings associated with providing care (Nijober *et al*, 1999b). The latter is especially important for caregiver well being and for predicting outcomes of caregiving (Pearlin *et al*, 1990).

1.7.1 Caregiver Stress Models

Lazarus and Folkman's (1984) transactional model of stress argued that stress results when an individual perceives a discrepancy between the number of perceived stressors they face and their perceived ability to cope with these stressors. They claimed that stress consists of three components, the process of noticing a threat *(primary appraisal)*, the process of responding to a threat *(secondary appraisal)* and the process of carrying out the response *(coping)* (Carver *et al*, 1989). Coping resources include factors such as socio-economic status, health and well-being, individuals' beliefs, and problem solving skills (Quine & Pahl, 1991).

The Stress Process Model, which is shown below (Pearlin *et al*, 1990), has been developed to highlight potentially important aspects of a caregiver's experience.

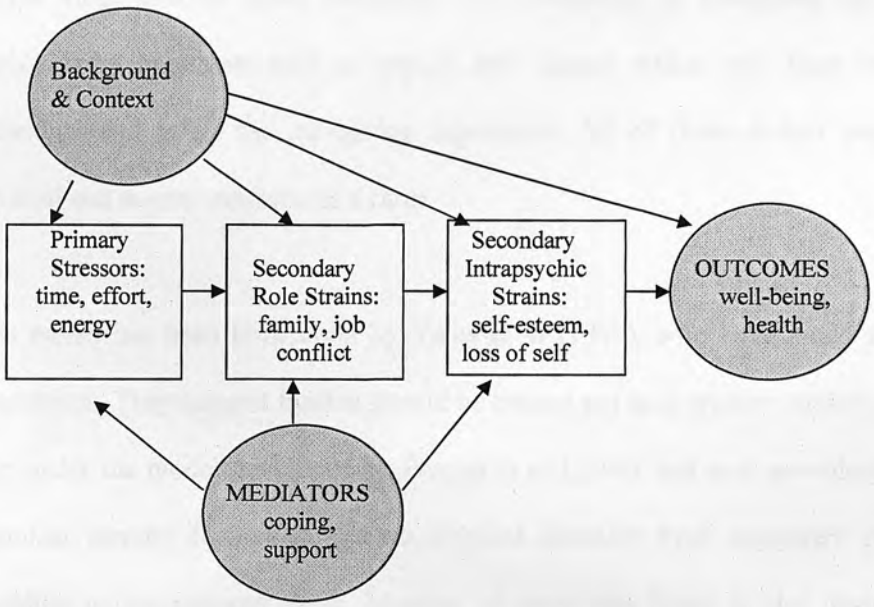

Figure 1.2: A Model of Caregiver Stress (Pearlin et al, 1990). Adapted by Zarit & Edwards (In Woods, 1996).

According to this model, caregiving experiences will depend on encountered stressors, existing coping mechanisms, and what point in their caregiving career a carer is at (Zarit & Edwards, 1996). An individual's background and context can shape the entire caregiving experience; often the stressors faced, the available resources and the expression of stress are affected by these environmental factors (Pearlin *et al*, 1990).

As well as contextual factors, the number and extent of both primary aspects (i.e. pertaining to the caregiving situation) and secondary aspects (i.e. those factors which affect other aspects of a carer's life outside of their caregiving role) can affect the experiences of an individual caregiver. As a consequence of persistent and often increasing demands placed on caregivers, their sense of self can be eroded leaving people vulnerable to stress outcomes. The variability in caregiving experiences is explained by mediators such as coping and support which vary from individual to individual and affect the caregiving experience. All of these factors can affect the physical and mental outcome of a carer.

This model has been built upon by Yates *et al* (1999), who have made a number of adaptations. They suggest burden should be treated not as a primary stressor, as was the case under the model developed by Pearlin *et al* (1990), but as a secondary subjective appraisal, thereby distinguishing care-recipient disability from caregivers' responses to disability within care-recipients. Number of caregiving hours is also designated as a primary appraisal by Yates *et al* (1999) who argue that caregivers assess level of need

required by the care-recipient. Once again therefore the amount of care provided is dependent on the caregiver's appraisal of need rather than the amount of disability exhibited by the care-recipient. Primary stressors (such as cognitive and behavioural impairment and functional disability) lead indirectly to caregiver depression via the perceived number of hours of caregiving required and perceived burden which is mediated by the relationship between caregivers and care-recipients, available social support and respite and caregiver self-efficacy (Chappell & Reid, 2002). In short, Yates *et al* (1999) conclude that in order for the Pearlin *et al* (1990) model to characterise the experience of caregiving accurately the above modifications may be necessary.

Caregiving appears to be a multi-dimensional experience affected by a number of factors such as presence of behavioural difficulties, available support and financial resources. Many caregiving studies fail to account for the multitude of factors which can affect caregiver burden and therefore may produce conclusions based on incomplete data (Rymer *et al*, 2002).

1.7.2 Types of Coping

Coping has been found to affect perceived levels of burden in both carers of individuals with dementia (Gilhooly, 1987) and carers of individuals with intellectual disabilities (Seltzer *et al*, 1995). Lazarus (1993) defined coping as

> "... ongoing cognitive and behavioural efforts to manage specific external and / or internal demands that are appraised as taxing or exceeding the resources of the person" (p237).

Coping research has identified a number of coping strategies. Problem focused coping involves the use of cognitive and behavioural problem solving strategies aimed at altering the environment in which the stressor occurs, and emotion focused coping aims to reduce emotional distress via cognitive or behavioural efforts (Kim *et al*, 2003). It is likely that problem focused coping offers the best method of dealing with stressful events, except for when a caregiver is faced with a situation in which nothing useful can be done to change the situation, in which case emotion focused coping would be preferable. Problem focused coping has been shown to reduce distress within parents of adults with intellectual disabilities (Kim *et al*, 2003). This type of coping was related to lower levels of subjective burden and depression in caregivers and better relationships between carers and care-recipients throughout this three year long study. Although general coping was measured, coping responses to specific stressors were not identified and it is possible that measuring coping specific to different situations or difficulties may produce different results.

A number of studies have found that the breakdown in community care for individuals with dementia is in fact more a consequence of caregiver well being than the severity of illness in the care-recipient (Gilhooly, 1986; Zarit *et al*, 1986; Gilleard, 1987). Attention has therefore begun to focus on the identification of coping techniques used by supporters in the community (McKee *et al*, 1997).

1.7.3 Caregivers of Individuals with Dementia

Caring for a relative with dementia has been found to be one of the most stressful and disruptive events in the family life cycle (Zarit & Edwards, 1996). It has been shown to have adverse effects on carers' mental health (Gilhooly, 1984a) and caring for individuals with dementia has been related to increased rates of caregiver depression (Schulz *et al*, 1995; Kiecolt-Glaser *et al*, 1989). However studies have failed to document a linear relationship between the severity of dementia and burden within caregivers (Vitaliano *et al*, 1991). The majority of these studies rely on caregivers to provide an accurate assessment of their relative's difficulties and fail to account for the possibility that some caregivers may either exaggerate or downplay the severity of their family member's problems (Rymer *et al*, 2002), thereby affecting the outcome of studies comparing the severity of dementia and caregiver burden.

It has been estimated that 50 per cent of people with Alzheimer's disease exhibit behavioural problems (Nagaratnam *et al*, 1998). Behavioural problems such as wandering, aggression, agitation, delusions, anxiety, irritability and disinhibition appear to be most related to caregiver burden (Rymer *et al*, 2002) as these can often be difficult for caregivers to deal with. Meiland *et al* (2005) found apathy, depression, agitation and irritability within care-recipients to be the most distressing psychiatric symptoms for caregivers to contend with. This is significant given that more than one third of all people with dementia are estimated to suffer from a co-morbid depressive disorder (Holtzer *et al*, 2005). While cognitive deficits in individuals with dementia show a linear pattern of decline, behavioural and psychological symptoms of dementia show a more

variable pattern (McCarty *et al*, 2000). It has therefore been argued that it is the unpredictability of these behavioural and psychological symptoms of dementia that lead to a reduction in overall caregiver well-being (Hooker *et al*, 2002). However, Meiland *et al* (2005) found that these symptoms could only explain 50 per cent of the variance in the emotional impact upon caregivers. Therefore other factors must also play a part in a caregivers' overall experience of burden. Placement of care-recipients within a nursing home has been shown to be predicted by both burden and depression levels (Dunkin & Anderson-Hanley, 1998) which remain important foci for future research.

Caregivers for a family member or friend with dementia can face a multitude of losses with the progression of dementia. They can be faced with the loss of a loved one as they previously knew and loved them (Prigerson, 2003). Also, because of the burden associated with caring for an individual with dementia, many families place their loved one in a nursing home (Pushkar Gold *et al*, 1995) and therefore caregivers can be faced with this loss also. As such, caregivers for individuals with dementia can find themselves simultaneously providing care and grieving (Prigerson, 2003). For spousal caregivers other losses can include a loss of both emotional and practical support, such as in making joint decisions or sharing activities (Baikie, 2002). When individuals' with dementia are less able to provide reciprocity and support within the marriage, this can lead to greater levels of depression within carers (Baikie, 2002).

It has also been found that placement does not necessarily result in reduced burden within caregivers. Tornatore and Grant (2002) concluded that nursing home placement

in fact increased caregiver burden in older family caregivers, in those who had been caring for shorter periods of time, and in those who had lower expectations for nursing home care. Low expectations regarding nursing home placement may reflect a lack of confidence or trust in these facilities and may result in increased visitation and hypervigilance of nursing home staff, leading to increased feelings of burden. It may also be that those carers, who had been caring for longer, experienced more relief upon placement than those who had been caring for shorter periods of time. Institutionalisation may create a new source of stress, which individuals who have not been caregivers for long may find more difficult to adapt to. Given that many family caregivers feel guilt after placing an individual with dementia into a nursing home (Nolan & Dellasega, 1999), it is also possible that these feelings are reduced in individuals who cared for a longer period of time, thus explaining why they experience less burden as a result of placement (Tornatore & Grant, 2002). Therefore, although placement is commonly used as a means of reducing caregiver burden and is frequently recommended by medical professionals, it may not have the effect of improving caregiver well-being.

1.7.4 Caregivers of Individuals with Intellectual Disabilities

As with caring for individuals with dementia, it has also been found that caring for those with an intellectual disability can have a negative effect on a carers' well-being (Bradshaw & Lawton, 1978). These carers are faced with a number of difficulties which can cause distress, such as a high level of physical care demands and behaviour problems (Seltzer *et al*, 1995). As carers age, they may also have to confront their own

or their family's ill-health and decisions about the future care of their loved one with an intellectual disability.

Carers of individuals with intellectual disabilities are often faced with the consequences of dealing with daily behavioural disturbances, psychological difficulties and physical dependencies which are all common co-morbidities in these care-recipients (McGrother *et al*, 2001). Behavioural difficulties have been shown to increase stress of caregiving in carers of people with intellectual disabilities (Heller *et al*, 1997). This is significant given that psychiatric and behavioural difficulties are around three to five times more prevalent in individuals with intellectual disabilities than in the normal population (Emerson *et al*, 1999). Specific behavioural difficulties that carers have identified as being difficult to deal with include offensive or socially disturbing behaviour, provocative behaviour or stereotypical behaviour (Maes *et al*, 2003). They often lead to a reduction in the quality of life of both the individual with the intellectual disability and their carers (Maes *et al*, 2003). Carers faced with caring for individuals with co-morbid intellectual and behavioural or psychiatric difficulties often experience greater burden and are more likely to require help from formal services (Maes *et al*, 2003). However without comparison samples and more longitudinal data, it is difficult to compare these caregivers with parents in the general population (Essex & Hong, 2005).

It has been estimated that 10 to 15 per cent of individuals with intellectual disabilities display behavioural difficulties (Emerson, 1998). Pahl and Quine (1987) found that distress within caregivers looking after dependents with intellectual disabilities was

associated with problem behaviours, night-time disturbance, the presence of multiple impairments and the dependent having an unusual physical appearance.

Financial worries and social isolation were also found to contribute to caregiver burden. Children with intellectual disabilities are more likely to live in poverty than their peers without disabilities (Parish & Cloud, 2006). Employment rates amongst carers for individuals with an intellectual disability have been found to be much lower than other households without a dependent with intellectual disabilities. Due to limited or non-existent day care or inflexible working conditions, one or both parents may have no choice but to remain at home with their disabled child (Parish & Cloud, 2006). This has perhaps contributed to the finding that carers of individuals with intellectual disabilities earn around 25 per cent less over their lifetime than the rest of the population (Jarbrink & Knapp, 1999). Although there were increases to the invalid care allowance in 2000, the issue of poverty faced by many carers of people with intellectual disabilities needs to be addressed further.

The literature on caregiver burden is largely related to those caring for individuals with dementia or chronic illness (McDermott *et al*, 1997) and as such there is limited information about the impact of caring on caregivers for individuals with intellectual disabilities. This is an important issue considering that carer strain has been shown to affect not only caregiver well-being, but also the outcome for the child, and in particular requests for long-term care of the care-recipient with intellectual disabilities (Sherman & Cocozza, 1984).

1.8 Caregiver Satisfaction: The Positive Aspects of Caring

This section will explore the positive aspects of caregivers' experiences, exploring: why it may be important to measure satisfaction; models of satisfaction and the experiences of caregiver satisfaction within carers of individuals with dementia and intellectual disabilities.

Caregiver satisfaction has been defined as "subjectively perceived gains from desirable aspects of or positive affective returns from caregiving" (Lawton *et al*, 1991). Providing care can be a very rewarding and satisfying experience. Despite the concept of caregiver satisfaction being developed over 20 years ago (Davies, 1980), there has only been a limited body of research since that time (Lundh, 1999; Nolan & Lundh, 1999). Satisfaction can be conceptualised in terms of who benefits from caring. Positive features have been identified which relate both to the enhancement of the care-recipients' life, the caregivers' life, and those which relate to mutual benefit (Nolan *et al*, 1996). However the limited research on this topic means that the concept of caregiver satisfaction is ambiguous and ill-defined.

1.8.1 The importance of measuring Caregiver Satisfaction

Throughout the care giving literature, the positive aspects of care giving have received less attention, with the majority of studies focusing on caregiver burden (Andrén & Elmstähl, 2005; Veltman *et al*, 2002). Twigg and Atkin (1994) express a concern that the dominance of burden within the research, and the development of policy initiatives

based on these studies, may pathologize the caregiving experience, both in caregivers of people with dementia (Lundh, 1999) and caregivers of people with intellectual disabilities (Quine & Pahl, 1991). In order to gain a more holistic understanding of caregivers' experiences, it is necessary that both burden and satisfaction be studied; indeed failing to assess the positive aspects of caregiving may bias results and invalidate conclusions (Kramer, 1997).

Gaining an estimate of caregiver satisfaction has many potential benefits. It may help to estimate risk factors such as poor caregiver well being, or risk of institutionalization or abuse, in addition to identifying those caregivers who may be unlikely to access formal services and therefore may require their needs to be met in other ways (Cohen *et al*, 2002). If professionals and services ignore the positive aspects of a carer's experience they may be perceived by caregivers as non-empathic and non-understanding, further hindering this vulnerable group's access to support.

Caregivers often appreciate the ability to express positive as well as negative emotions regarding their experiences (Jones, 1996), and this does not appear to be affected by either caregiver health or caregiver burden (Andrén & Elmstähl, 2005). In a study of Canadian caregivers, Cohen *et al* (2002) interviewed a range of caregivers, caring for older people in the community and enquired about their experiences. They asked carers an open-ended question enquiring whether they could identify any positive aspects of caregiving. Volunteers were also given ten forced choice (Yes/No) questions relating to positive aspects of caring. Over two-thirds of carers identified one positive feature in

their caregiving role; the most cited positive aspects of caregiving were gaining companionship or fulfillment from their role as a carer. Carers who reported greater numbers of positive aspects where also less likely to report feelings of burden or poor health; factors which have been shown to correlate with increased mortality for the caregiver (Schulz & Beach, 1999) and increased institutionalization for the care-recipient (Cohen *et al*, 1993). Although this does not explain whether identifying more positive aspects within a caregiving role is a protective factor, decreasing the risk for poor well-being, or whether some factors are more protective than others, it does highlight the importance of caregiver satisfaction and the need for clinicians to enquire about this aspect of carers' experiences.

1.8.2 Caregiver satisfaction Models

Grant and Nolan (1993) identified three major sources of satisfaction; those derived from the interpersonal dynamic between the caregiver and the care-recipient, those stemming from the carer themselves and those originating from the desire to promote positive or avoid negative outcomes for the care-recipient. These satisfactions are seen to relate to interpersonal, intrapersonal and outcome factors. Nolan *et al* (1996) represented this information in the following matrix:

Primary direction of perceived benefit		Derivation of satisfaction: Interpersonal dynamic	Derivation of satisfaction: Intrapersonal/ intrapsychic dynamic	Outcome dynamic
	Cared-for person ↑	Maintaining/providing small pleasures, Seeing cared-for person happy, Maintaining dignity/ self esteem of cared-for person	Nurturance and tending	Providing best care available, Avoiding institutionalization, Helping cared-for person reach full potential, development and growth Aiding recovery
	Shared	Closer caring relationships, Improved family relationships	Developing family values and meanings, Repayment of past kindness, Hypothetical exchange, Altruistic behaviour	Developing new shared interests
	Carer ↓	Expressions of appreciation from: - cared-for person - family/friends - professionals Love and affection from cared-for person		Developing new skills and abilities

Figure 1.3: Exploring the satisfactions of care: a completed matrix (Nolan et al, 1996).

As can be seen from the above matrix, examples of satisfactions derived from the care-recipient include factors such as maintaining the dignity of the care-recipient, providing nurturance and avoiding institutionalisation. For the caregiver themselves, satisfactions include feeling appreciated by the care-recipient or developing new skills and abilities as a result of caring. Shared satisfactions, i.e. those benefiting both caregivers and care-recipients include developing closer relationships with family, repaying past acts of kindness and developing new shared interests.

Following from this work on the satisfactions within caregiving, Nolan *et al* (1998) developed the Caregiver Assessment of Satisfaction Index (CASI), which sought to measure the above-mentioned satisfactions in a range of carers. This measure will be discussed in greater detail within the methods section of this thesis.

1.8.3 Caregivers of Individuals with Dementia

A number of factors have been found to provide satisfaction for caregivers caring for individuals with dementia. For example giving pleasure to a dependent, maintaining the dignity of the care-recipient, and maximising the care-recipient's potential, have been identified as potentially satisfying reasons to provide care within dementia caregivers (Nolan *et al*, 1996; Lundh, 1999).

In addition love, reciprocity and commitment have been cited as key motivations in family caregiving of individuals with dementia (Motenko, 1989). For many, caregiving can represent the demonstration of an emotional attachment to a loved one (Motenko, 1989).

A particularly potent form of reward comes from expressions of gratitude from the care-recipient (Grant & Nolan, 1993). This mutuality, defined as the ability to find gratification and meaning and a sense of reciprocity within the relationship (Hirschfield, 1983) may decrease with reduced cognitive capacity, and may therefore affect the amount of satisfaction felt by caregivers of individuals with dementia as the illness progresses. In a study of wife caregivers, Kramer (1993) suggests that close, loving prior

relationships may lead these women to be more committed and less resentful of their caregiving role. Lundh (1999) used the Caregiver Assessment of Satisfaction Index (CASI) to assess satisfaction among Swedish carers. In this study, most carers identified satisfactions related to bringing pleasure to the care-recipient, maintaining the dignity of the supported individual and keeping the recipient out of an institution.

Andrén and Elmstähl (2005) used the Caregiver Burden Interview (CBI, Zarit et al, 1980) and the Caregiver Assessment of Satisfaction Index (CASI; Nolan et al, 1998) to assess levels of dissatisfaction and satisfaction respectively in a community sample of dementia caregivers. Common sources of satisfaction related to the cared for person being well 'turned out', having pleasure, being happy and having their dignity maintained. Satisfactions related to the caregivers themselves indicated feeling needed and wanted and being appreciated for what they do. Expressions of love, and knowing that the care-recipient would do the same for them (reciprocity) were among the shared benefits identified. The least satisfying aspects on the CASI related to items indicating that caring had increased contacts and interests and developed new skills and abilities. Ratings of satisfaction were found to be unrelated to experiences of burden or well-being. It should be noted that the dementia carers in Andrén and Elmstähl's (2005) study received support from both informal and formal caregivers, and as such these results may not generalise to those caregivers not receiving any formal help. The self-selecting nature of recruitment into this study may mean that this sample is not representative of caregivers as a whole; perhaps only those who experience satisfaction in their role responded to invitations to take part in the study.

The above studies attempt to quantify levels of satisfaction within caregivers using psychometrics. As a result, other aspects of satisfaction from the caregiver experience may have been missed. Although this standardised process has its advantages, not least of which, the ability to compare different individual caregivers' experiences, perhaps a more detailed measure of caregiver satisfaction may come from more qualitative methodologies. Despite these limitations, the above studies show that carers, in a variety of different countries and cultures, identify common sources of satisfaction relating to maintaining the dignity of the care-recipient and providing pleasure for them.

1.8.4 Caregivers of Individuals with Intellectual Disabilities

The shift in focus in caregiving literature, looking at positive aspects of caregiving, has been slower in this group of carers (Green, 2007). However a number of studies have found that caregivers of individuals with intellectual disabilities identify benefits of caregiving, including increased confidence (Schwartz & Gidron, 2002) and developing reciprocal supportive relationships (Heller *et al*, 2003). In a recent study, Green (2007) developed five positive statements to assess the benefits of caring within a population of mothers caring for children with intellectual disabilities, and found a high rate of agreement with these statements indicating these mothers experienced benefits within their caregiving roles. However as this study did not provide any comparison group of mothers of children without disabilities, it is hard to conclude which benefits are relevant to all parents and which benefits pertain only to parents of individuals with intellectual disabilities.

Within a Swedish sample of caregivers, giving pleasure to a dependent, maintaining the dignity of the care-recipient, and maximising the care-recipients potential, were identified as potentially satisfying reasons to provide care (Lundh, 1999) for this group of carers.

Caregivers themselves also seem to gain from the caring experience. They often report having a closer current relationship with the care-recipient in comparison to the onset of their caregiving relationship (Clifford, 1990; ABS, 1998). Ashworth and Baker (2000) found caregivers had an increased sense of self esteem and Lundh (1999) reported that caregivers felt they had developed as a person since beginning caregiving; a concept Pearlin *et al* (1990) termed "personal gain".

Winik *et al* (1985) found that adults with intellectual disabilities were unlikely to view support provided by parent caregivers as something which should be reciprocated. Even those with mild disabilities, expected assistance but did not expect to give anything in return. Since reciprocity within a caregiving relationship has been shown to relate to caregiver satisfaction (Lundh, 1999), it may follow that caregivers of intellectually disabled adults express less satisfaction with their role. A lack of reciprocity with the caregiving relationship may limit the amount of satisfaction received from caregiving.

1.8.5 Summary

Therefore, although the research is limited in the area of caregiver satisfaction, studies have begun to explore the positive aspects to caregiving. An important finding remains that caregivers can experience both burden and satisfaction (Andrén & Elmstähl, 2005). It may also be important to note that caregiver satisfaction can at times serve to bind a caregiver to a caring situation which perhaps should not be sustained (Nolan *et al*, 1996).

1.9 Research aims, questions and hypotheses

1.9.1 Research aims

The general aims of this study are to explore the characteristics of carers of people with dementia and carers of people with an intellectual disability residing in a local NHS Trust in Scotland. Using previously developed instruments, levels of burden, satisfaction and caregiver well-being experienced by informal caregivers of individuals with dementia and intellectual disabilities will be measured.

1.9.2 Research questions and hypotheses

1.9.2.1 Primary research questions and hypotheses

1) **Does caregiver satisfaction differ between the carers of individuals with dementia and the carers of individuals with an intellectual disability?**

Hypothesis 1: *It is hypothesized that caregiver satisfaction will differ as a function of the type of care-recipient diagnosis; therefore it is predicted that caregivers of individuals with an intellectual disability will report greater satisfaction than caregivers of individuals with dementia.*

2) Does caregiver burden differ between the carers of individuals with dementia and the carers of individuals with an intellectual disability?

Hypothesis 2: *It is hypothesized that caregiver burden will differ as a function of the type of care-recipient diagnosis; therefore it is predicted that caregivers of individuals with dementia will report greater burden than caregivers of individuals with an intellectual disability.*

3) Does caregiver well being affect perceptions of satisfaction?

Hypothesis 3: *It is hypothesized that caregivers' reported well-being will differ depending upon the satisfactions of caregivers; therefore it is expected that those caregivers who report greater well-being will also report greater levels of satisfaction with caregiving.*

4) Does a caregiver's gender affect the level of satisfaction reported by carers of individuals with dementia and the carers of individuals with an intellectual disability?

Hypothesis 4: *It is hypothesized that caregiver satisfaction will vary depending on the gender of the caregiver; therefore it is predicted that female caregivers will express less satisfaction than male caregivers.*

1.9.2.2 Secondary research hypotheses

In addition to the above hypotheses, it is also expected that certain caregiver characteristics will also impact on caregiver outcome. Factors such as kin relationship, in addition to care-recipient severity of difficulties will have an impact on levels of burden and satisfaction.

CHAPTER 2: METHODOLOGY

2.1 Design

This study utilized a cross-sectional independent groups design in which two groups of carers, those caring for individuals with dementia and those caring for individuals with intellectual disabilities, were assessed on the five self-report questionnaires listed below. The variables to be measured were caregiver satisfaction, caregiver burden, caregiver well-being and care-recipient difficulties. This design permitted the examination of the strength of associations between these variables and the groups of caregivers.

2.1.1 Ethical Approval

The research design was approved by the Local Research and Ethics Committee (LREC) (see Appendix 1) and the local Research and Development (R&D) Department (see Appendix 1).

2.1.2 Ethical Considerations

Information gathered at interview and through the use of questionnaires was confidential. However it was agreed that appropriate agencies would be notified of any individual experiencing difficulties or distress. Suitable communication pathways to Community Learning Disability Teams and Community Mental Health Teams within the local area were developed in case these circumstances arose. As all participants were known to one of these services referral pathways were not

necessary. Although every attempt was made to minimize the risk of producing distress in participants, the possibility that volunteers may experience distress was recognized. Therefore it was essential for the researcher to be sensitive to the needs of participants and to integrate this approach into the interviews that were conducted. Each participant was informed of their right to refuse to answer any distressing question, in addition to their right to withdraw from the study at any time, without providing a reason (see consent form; Appendix 2).

2.2 Participants

Fifty individuals were recruited from learning disability and dementia services within a local NHS Trust in Scotland. A total of 38 females and 12 males took part in this study.

2.2.1 Inclusion Criteria

Participants were adults aged 18 years or over and were the main informal caregiver of an individual who had been diagnosed with either dementia or an intellectual disability. Due to the reliance on questionnaire completion, all volunteers were required to have adequate literacy skills, which enabled them to read and understand English. Where more than one informal caregiver shared the caregiving

responsibilities for a care-recipient, and where both opted to take part in the study, both carers were interviewed and completed questionnaires.[1]

2.2.2 Exclusion Criteria

Individuals were excluded from the study if they were unable to read or understand English. Carers who were formal caregivers or those who were not the main informal caregiver were also excluded. Carers who were caring for individuals with other disorders i.e. physical health difficulties were not included in this study, unless they had also received a diagnosis of dementia or an intellectual disability.

2.2.3 Dementia Caregivers Sample

Participants were recruited from the Community Mental Health Team for Older People (CMHT-OP), Early Onset Dementia Service and Alzheimer's Scotland groups within the local area. Early onset Dementia service and Alzheimer's Scotland carers' meetings were attended, where the researcher was able to discuss the study, explain what participation in the study would involve and answer any questions. At the end of these presentations, an information pack, consisting of an information sheet (Appendix 3 & 4), an opt-in form (Appendix 5) and a stamped addressed envelope were provided to group members. Individuals who wished to participate in this study therefore filled their contact details into the opt-in form and returned it to the chief investigator in the envelope provided.

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[1] Where caregivers shared responsibilities the data was analysed as independent data.

Within the liaison service of the CMHT-OP, three nursing homes were identified and approached regarding this study. Each nursing home contained a dementia unit. The researcher met with the care home managers in order to discuss the study and answer any questions they may have. In order to maintain confidentiality care home managers identified appropriate carers (based on the inclusion and exclusion criteria) and provided them with information packs regarding the study. As before, these information packs included an information sheet, opt-in form and stamped addressed envelope. If individuals consented to participate in the study they completed the opt-in form, which provided their contact details and returned it to the researcher in the stamped addressed envelope.

Individual caregivers were also recruited from CMHT-OP staff members' caseloads. Multi-disciplinary team members within the CMHT-OP met with the researcher in order to obtain information on the study and have the opportunity to ask questions. Potential participants were identified and given information packs containing an information sheet, opt-in form and stamped addressed envelope. Those caregivers, who wished to participate, completed their contact details on the opt-in form and returned it in the stamped addressed envelope to the researcher. All participants at time of participation in the study had time to read the information and consent forms, ask questions and then at least 24 hours to consider whether or not to participate in this study.

2.2.4 Intellectual Disability Caregivers Sample

Caregivers of individuals with an intellectual disability were recruited from Community Learning Disability Teams in the local NHS Trust in addition to three physiotherapy led groups for carers of individuals with intellectual disabilities. The researcher attended a multi-disciplinary team meeting for both the North and South Community Learning Disability Teams in the local NHS Trust and gave a presentation on the study, outlining what multi-disciplinary team members would be required to do if they chose to help identify caregivers for individuals with intellectual disabilities and what would be involved for the caregivers if they volunteered to take part. There was also the opportunity to ask questions at this stage regarding the research. Multi-disciplinary team members then identified potential caregiver participants. To ensure confidentiality and prevent caregivers being asked to participate by more than one team member, names of potential participants were then passed to the Secretary of the Psychology department within the Community Learning Disability Team who removed duplicated names and sent information packs to the remaining candidates. Therefore the researcher was unaware of individuals who accessed this service, until caregivers opted in to the study by completing their contact details on an opt-in form and returning it to the researcher in a stamped addressed envelope.

Physiotherapy led groups, for caregivers of individuals with intellectual disabilities, were attended by the researcher. It was then possible to present group members with details about the study and to answer any questions they may have. Once again

group members were given information packs including an information sheet and an opt-in form, which they could complete and return in the stamped, addressed envelope provided.

2.2.5 Postal Responses

Due to an inability to meet face-to-face with the researcher a total of seven participants requested that the information schedule and questionnaires be posted to them. Completed questionnaires were returned, along with the completed information schedule, to the researcher in a stamped addressed envelope.

2.2.6 Response Rate

Due to confidentiality reasons, the researcher was unable to gather precise information on how many caregivers were sent information regarding this study. Therefore it is not possible to calculate an exact response rate of individuals who opted to take part in the study. However around 150 information sheets where sent out to carers and 50 consented to take part. This constitutes a response rate of 33 per cent.

2.3 Measures

A total of five questionnaires where used to assess carer satisfaction, carer burden and carer well-being. In addition caregiver and care-recipient characteristics were also assessed.

2.3.1 Demographic Information Schedule

In order to obtain information regarding demographic characteristics and other important variables, an information schedule was developed by the researcher (Appendix 6). This caregiver information schedule was based on information thought to affect carers' perceptions of satisfaction and burden (López *et al*, 2005). The information schedule assessed the following aspects:

Characteristic	Related to Caregiver	Related to Care-recipient
age	x	x
sex	x	x
kin relationship	x	x
marital status	x	x
occupation	x	
living arrangements		x
received diagnosis		x
duration of caregiving career	x	
types of caregiving duties	x	
length of time spent caring	x	
other dependents	x	
subjective rating of past and present relationship	x	
subjective rating of caregiver health	x	
subjective rating of severity of dementia / learning disability		x

Table 2.1: Caregiver Characteristics assessed as part of Information Schedule. Developed by the author.

Demographic information on caregivers' age, sex, marital relationship, relationship to the care-recipient, occupation outside of caregiving, duration of caregiving career, types of caregiving duties, daily time spent caregiving and the number of other dependents in the household. Care-recipients' age, sex, marital status, relationship to

the caregiver, living arrangements and diagnosis were recorded. Lastly caregivers' subjective ratings of their own health, the severity of dementia or intellectual disability within care-recipients, as well as ratings of past and current relationships with the care-recipient were also obtained.

2.3.2 Carers Assessment of Satisfaction Index (CASI; Nolan *et al*, 1998)

Caregiver satisfaction was assessed using the Carers' Assessment of Satisfaction Index (CASI; Nolan *et al*, 1998). A 30-item questionnaire (Appendix 7), the CASI consists of 10 items associated with the care recipient, 12 associated with the caregiver themselves, with the remaining 8 items related to interpersonal dynamics. Each item is rated on a four point scale ranging from zero (doesn't apply) to three (applies and provides a great deal of satisfaction).

The CASI is one measure in a collection of three; and although it identifies the degree of carer satisfaction, Nolan *et al* (1998) also developed other measures, which indicate difficulties (Carers Assessment of Difficulties Index, CADI) and coping strategies utilized (Carers Assessment of Management Index, CAMI) within a caregiving role. The CASI can therefore be used individually or as part of this collection.

Whilst the CASI can be used to look at the prevalence of satisfactions, it was originally developed to provide an individual profile of carers' experience (Nolan *et al*, 1998). As such it may be less meaningful to tally items with this instrument in

order to provide a total score, nor for comparing one carer to another. Nolan *et al* (1998) point out however that the CASI can be used to find out about common satisfactions within a population of carers, or to determine whether there is any variation within sub-groups of carers. The CASI has a Cronbach's alpha of .91 suggesting that it has high reliability and internal consistency (Nolan *et al*, 1998).

2.3.3 Caregiver Burden Interview (CBI, Zarit *et al*, 1980)

The Caregiver Burden Interview was used to measure carer strain (Appendix 8). This measures caregivers' emotional well being, social and family life, finances and degree of control over their life (Rymer *et al*, 2002). The CBI is a 22-item self report measure, which is rated on a five-point scale ranging from never to nearly always. Scores range from 0 (low burden) to 88 (high burden). A score of 20 or less suggests the rater is experiencing no or minimal burden. Scores of above 20 suggest the rater is experiencing some degree of burden; with 21-40 suggesting mild to moderate burden, 41-60 suggesting moderate to severe burden and 61-88 suggesting severe burden. This measure is a standardized, validated, reliable tool for the assessment of burden of caregivers and it has been widely used in caregiver research (O'Rourke & Tuokko, 2003). It is quick to administer and is acceptable to relatives (Oyebode, 2003).

2.3.4 Memory and Behaviour Problems Checklist (MBPC; Teri *et al*, 1992)

The Memory and Behaviour Problems Checklist is a 30-item instrument that measures observable problems exhibited by a dependent person and their impact on

the caregiver (Appendix 9). This measure provides an excellent assessment of care-recipient centred problems (Vitaliano *et al*, 1991) and strong reliability and validity (Teri *et al*, 1992).

Although the MBPC was originally developed for use with caregivers of people with dementia it has also been used to look at care-recipient difficulties and their effect on caregivers in other populations e.g. Caregivers of individuals with Acquired Brain Injury (Jackson et al, 2007), Caregivers of disabled older adults (Clark, 2002), caregivers of individuals with non-dementia memory problems (Wackerbarth et al, 2001) and caregivers of cognitively impaired individuals (Novak & Chappell, 1996). It is however recognised that a measure specific to caregivers of individuals with intellectual disability may be more sensitive to memory and behaviour difficulties associated with intellectual disability. For example the Aberrant Behaviour Checklist (Aman & Singh, 1994) or the Vineland Adaptive Behavior Scales (Sparrow et al, 1984) may be used to look at behavioural difficulties in individuals with intellectual disability. However to aid comparison, it was felt necessary to use only one questionnaire in order to assess memory and behaviour difficulties within this sample; therefore the MBPC was used.

2.3.5 Beck Depression Inventory (BDI; Beck *et al*, 1979)[2]

The Beck Depression Inventory was used to assess levels of depression within caregivers (Appendix 10). The BDI is a 21-item self-report measure, rated on a four-point scale.

The BDI has been recommended for use in assessing depression both in clinical practice and research studies. The internal consistency has been found to be high (Steer *et al*, 2000). Beck *et al* (1988) have also found the BDI to have high content and discriminant validity. A score of 20 or over would suggest moderate to severe depression.

2.3.6 Beck Anxiety Inventory (BAI; Beck *et al*, 1990)

The Beck Anxiety Inventory was used to assess the degree of anxiety within caregivers (Appendix 11). This measure is also a 21-item self-report measure, which is rated on a four-point scale.

Like the BDI, the BAI is also recommended for use in assessing anxiety in clinical practice and research studies. The BAI has been found to have high internal consistency (Beck *et al*, 1988). A score of 16 to 25 would suggest moderate levels of anxiety and 26 or over, severe levels of anxiety.

ıe BDI and the BAI were used as negative indicators of well-being i.e. a lower score on each measure used to indicate greater well-being. A specific measure of well-being (the Warwick-Edinburgh Mental lbeing Scale) was developed after this study took place.

2.4 Procedure

2.4.1 Caregivers of Individuals with Dementia

Caregivers of individuals with dementia were assessed either in their own homes or within a hospital in the NHS Trust where the researcher was based. The researcher confirmed the participant had received an information sheet (Appendix 3), regarding the purpose of the study, and they were provided with the opportunity to ask any questions at this time. Participants were asked to read over the participant consent form (Appendix 2) and if willing to sign and date it. All participants had time to read the information and consent forms, ask questions and then had at least 24 hours to consider their participation in this study. Each participant was given a copy of their consent form to keep for his or her own records. It was explained by the researcher that all information was confidential and that completed questionnaires would be stored in a locked cabinet. Participants were also made aware of the fact that their name would be replaced with an identification number for analysis of information.

Assessment involved the administration of a semi-structured interview, along with the five questionnaires listed above. The researcher read aloud the instructions for each questionnaire and completed the questionnaires and information schedule based on participants' responses. Due to fact the semi-structured interview took the format of the demographic information schedule, no information was lost for the seven participants who completed questionnaires and returned them by post. Following

completion of the questionnaires, participants were thanked for taking part in the study and were asked if they wished to receive a summary of the results upon completion of the study. The contact details of those participants wishing to receive a synopsis of the study results were confirmed. Completed questionnaire packs were stored in a locked cabinet and participants were allocated an identification number in preparation for data entry.

2.4.2 Caregivers of Individuals with Intellectual disabilities

The procedure for caregivers of individuals with intellectual disabilities was identical to that explained above for caregivers of individuals with dementia. Participants in this group were assessed either in their own homes or at the hospital where the researcher was based. At this time it was confirmed that they had received an information sheet (Appendix 4) and there was the opportunity to ask any questions they may have regarding the study. Two copies of the consent form (Appendix 2) were then signed, one for the researcher's records and one for participants to keep. It was explained that all information was confidential and that completed questionnaires would be stored in a locked cabinet. Participants were also made aware of the fact that their name would be replaced with an identification number for analysis of information. All participants had time to read the information and consent forms, ask questions and then had at least 24 hours to consider their participation in this study.

Assessment involved the administration of a semi-structured interview, along with the five questionnaires listed above. The researcher read aloud the instructions for each questionnaire and completed the questionnaires and information schedule based on participants' responses. Following completion of the questionnaires, participants were thanked for taking part in the study and were asked if they wished to receive a summary of the results upon completion of the study. The contact details of those participants wishing to receive a synopsis of the study results were confirmed. Completed questionnaire packs were stored in a locked cabinet and participants were allocated an identification number in preparation for data entry.

Due to the nature of recruitment all participants had more than twenty-four hours in order to decide if they wished to participate in this study.

2.5 Power Calculation

Power calculations were based on a study by Whittick (1988) who investigated levels of distress within caregivers of individuals with dementia and intellectual disability. Using two-tailed significance levels, 80 per cent power and alpha set at $p<0.05$, the total sample size estimated using t was 52. Therefore at least 26 participants would need to be recruited in each group to achieve power at this level.

CHAPTER 3: RESULTS

3.1 Statistical Analysis of Results

Data analysis was carried out using SPSS Version 11.0 for Windows Student Version. Tests of normality indicated that both parametric and non-parametric tests should be used (see Section 3.3) in the analysis of the data. Descriptive statistics, Independent T-Tests, ANOVAs, and chi-square correlations were used. Pearson's chi-square test was used to examine if there were any relationships between participant characteristics within groups. Independent t-tests were used to determine if any significant differences existed between caregivers of individuals with intellectual disabilities and caregivers of individuals with dementia in the amount of satisfaction and burden they experienced. In order to determine the effects that caregiver satisfaction, caregiver burden and caregiver well-being had on each other, a correlation matrix was carried out using Spearman's correlation. Analysis of variance was then used to compare caregiver levels of satisfaction and burden depending on kin relationship.

The significance level was set at 0.05. This decreases the chance that a difference between the caregiver groups will be missed, whilst limiting the chance that a difference between caregiver groups will be detected when in fact none exists (Field, 2005).

3.2 Participant Demographics

A total of 50 participants took part in this study:

- 19 caregivers of individuals with intellectual disabilities (ID group)
- 31 caregivers of individuals with dementia (Dementia group)

Background characteristics of the family carers who took part in this study can be seen in Table 3.1. Analyses for caregiver and care-recipient characteristics can be seen in Appendix 12 and 13. Over three quarters (76%) of caregivers were female (n=38), and just under one quarter were male (n=12). Seventy-six per cent of participants were aged 65 or less, and almost half (48%) of all caregivers were aged between 50 and 65 years. The mean age of caregivers for individuals with dementia was 57 years, whilst the mean age of caregivers for individuals with intellectual disabilities was 52 years.

Kin relationship differed depending on carer group; all carers of individuals with intellectual disabilities were parents (n=19), whilst there were similar numbers of both spouse (n=16) and child (n=12) carers for individuals with dementia. The remaining carers in the dementia group were comprised of one daughter-in-law, one sibling and one neighbour. All but six caregivers were married (n=44), three were widowed, one was single, one was separated and one was divorced.

	Dementia (n=27)		Intellectual Disability (n=17)		Summary statistics		
aracteristic	**Mean**	**SD**	**Mean**	**SD**	***df***	**t**	***p***
Age of Caregiver	57.48	11.27	52.26	10.42	48	1.635	.109
Caregiver health rating	6.06	2.94	6.00	3.25	48	.072	.943
Age of Care-recipient	71.06	13.19	20.26	10.37	48	14.285	.0005
Severity of difficulties rating	6.87	2.13	5.42	1.87	48	2.449	.018
Length of caregiving career	9.39	9.59	18.68	11.38	48	3.099	.003
regiver Characteristics	**%**	**N**	**%**	**N**	***df***	χ^2	***p***
Gender					1	1.133	.332*
Male	29	9	16	3			
Female	71	22	84	16			
Age Category					1	.146	1.000*
<65 years	74	23	79	15			
65 years or >	26	8	21	4			
Marital Status					1	1.414	.380*
Married	84	26	95	18			
Not Married (Single, Widowed, Divorced)	16	5	5	1			
Occupation					1	3.889	.049
Employed	45	14	74	14			
Unemployed	55	17	26	5			
Length of Caregiving					1	12.462	.0005
>8 years	39	12	89	17			
<8 years	61	19	11	2			
Hours spent Caring					1	3.095	.079
>9 hours	48	15	74	14			
<9 hours	52	16	26	5			
Kin Relationship					3	50.000	.0005
Spouse	32	16	0	0			
Child	24	12	0	0			
Parent	0	0	38	19			
Other	6	3	0	0			
Rating of past relationship					1	.333	.727*
Poor or OK	19	6	26	5			
Good or better	81	25	74	14			
Rating of current relationship					1	.734	.392
Same or better	68	21	79	15			
Worse	32	10	21	4			
re-Recipient aracteristics	**%**	**N**	**%**	**N**	***df***	χ^2	***p***
Gender					1	1.746	.186
Male	39	12	58	11			
Female	61	19	42	8			
Marital Status					1	17.238	.0005
Married	58	18	0	0			
Not Married (Single, Widowed)	42	13	100	19			
Residence					1	3.311	.069
With caregiver	42	13	68	13			
Not with Caregiver	58	18	32	6			

*Fisher's Exact P Value used

ble 3.1: Characteristics of Research Participants

The majority of caregivers for individuals with intellectual disabilities were employed (74%), compared to 45 per cent of caregivers for individuals with dementia. Participants were asked to rate their own health on a likert scale (0-10). Both groups of caregivers had a mean health rating of 6 (i.e. medium good health). Caregivers were also asked to rate both their past and current relationship with the care-recipient. Seventy-eight per cent of carers rated their previous relationship with the care-recipient as either good or very good, and seventy-two per cent felt their relationship with the care-recipient had either remained the same or gotten better since their loved ones were diagnosed. No difference was found between the two groups of carers on ratings of past or current relationship.

Over half (54%) of all care-recipients were female, and 46 per cent were male. Care-recipients in the dementia group had a mean age of 71 years, whilst those within the intellectual disabilities group had a mean age of 20 years. Around half of all care-recipients lived with their family caregiver (n=26; 52%), whilst a total of 15 (30%) lived in their own home, and nine care-recipients (18%) lived in a nursing home. All care-recipients with a diagnosis of intellectual disability were single, whereas over half of care-recipients with a diagnosis of dementia were married.

As can be seen from Table 3.1, the mean values suggest that there were no significant differences between the two groups on characteristics such as caregiver age ($t(48)=1.635$; $p=.109$; 2-tailed), and caregiver health self reports ($t(48)=.072$; $p=.943$; 2-tailed). A significant relationship was found between caregiver group and length of

caregiving career (t(48)=3.099; p=.003; 2-tailed). Mean length of caregiving was nearly nine years longer for caregivers of individuals with intellectual disabilities compared to caregivers for individuals with dementia.

Significant differences were also found between the two groups when comparing age of the care-recipient (t(48)=14.285; p=.0005; 2-tailed), and caregivers' ratings of severity of difficulties within care-recipients (t(48)=2.449; p=.018; 2-tailed). Given that most individuals who develop dementia are elderly, it is not surprising that this group had a higher mean age than those care-recipients within the intellectual disabilities group. The fact that caregivers in the dementia group rated their relative's difficulties as more severe than caregivers within the intellectual disabilities group may suggest that participants in this sample perceived dementia to be related to more severe difficulties than intellectual disability.

Caregivers within the two groups did not differ on factors such as gender (χ^2=1.133; df=1; p=.332), caregiver age category (χ^2=.146; df=1; p=1.000), marital status (χ^2=1.414; df=1; p=.380), number of hours spent caring (χ^2=3.095; df=1; p=.079), nor ratings of relationship quality (past (χ^2=.333; df=1; p=.727) and present (χ^2=.734; df=1; p=.392)), suggesting that the groups did not differ on these variables. There was a significant association between caregiver group and employment status of caregivers; carers of individuals with intellectual disabilities were more likely to be employed than carers of individuals with demntia (χ^2=3.889; df=1; p <.05).

Care-recipient characteristics did not differ on gender (χ^2=1.746; *df*=1; *p*=.186), or residence (χ^2=3.311; *df*=1; *p*=.069). However associations were found between marital status (χ^2=17.238; *df*=1; *p*=.0005) and caregiver group. Therefore care-recipients who had received a diagnosis of intellectual disability were less likely to be married.

When looking at caregiver gender, age category, marital status and past relationship quality between the two groups, there were expected counts below 5, which violate one of the chi-square test assumptions and opens up the possibility that the chi-square test may be inaccurate. If more time were available, the best remedy here would be to collect more data to try and boost the proportion of cases falling into each category (Field, 2005), in order to obtain more accurate associations between variables. Due to time constraints, further data collection was not possible. Therefore Fisher's exact tests were used for those associations were there were expected counts of less than 5.

3.3 Tests of Normality

In order to determine whether parametric or non-parametric tests should be used, the data were analyzed in order to determine if it deviated from a normal distribution. The Kolmogorov-Smirnov and Shapir-Wilkes Tests were used to test whether the distribution of scores significantly deviated from normal. These tests, together with histograms indicated the distribution of data was normal when comparing caregiver

ıtisfaction (Appendix 14), caregiver burden (Appendix 15) and care-recipient memory nd behaviour problems (Appendix 18). Therefore parametric tests were used to analyse ıese sets of data. However data collected for caregiver well-being (i.e. levels of epression and anxiety) were non-normal and therefore non-parametric tests were used) analyse this data (Appendix 16, 17).

.4 Main Hypotheses & Research Questions

.4.1 Hypothesis 1:

It is hypothesized that caregiver satisfaction will differ as a function of the type of caregiver; therefore it is predicted that caregivers of individuals with an intellectual disability will report greater satisfaction than caregivers of individuals with dementia.

.s shown by Table 3.2, there was a significant difference between caregiver groups in :lation to satisfaction (t(47)=3.039; p=.004; 2-tailed) (see Appendix 19).

	Care-recipient diagnosis	N	Mean (S.D)	t	p (2 tailed)
aregiver assessment of ıtisfaction index	Dementia	30*	44.77 (16.72)	3.039	.004
	Intellectual Disability	19	59.63 (16.62)		

)ne participant in the dementia group failed to complete CASI therefore n=30
.evene's test of homogeneity of variance was conducted for each comparison and is non-significant
ıless otherwise stated

'able 3.2: Caregiver Satisfaction within Caregivers [a]

'aregiver satisfaction was found to be greater in participants caring for individuals with ıtellectual disabilities. Due to the number of tests performed and the small sample size,

a Bonferroni Correction was applied to the significance level ($p<.005$) in order to reduce the chance of type I error (Field, 2005). Even then, there remained a significant difference between levels of satisfaction within these two groups of carers. Therefore the null hypothesis can be rejected at this stage and the proposal that caregiver satisfaction differs as a function of caregiver group is supported.

The measure used to assess satisfaction, the Carer Assessment of Satisfaction Index (CASI) contains three subscales; satisfactions primarily related to the care-recipient, satisfactions primarily related to the caregiver and satisfactions relating to interpersonal dynamics. Table 3.3 shows the results obtained when caregivers were compared on these three subscales. A significant difference was found between the subscale pertaining to satisfactions relating to the care-recipient and satisfactions relating primarily to interpersonal dynamics but not to the subscale relating primarily to the caregiver.

	Diagnosis of care-recipient	N*	Mean (S.D)	t (*df*)	*p* (2 tailed)
Satisfactions relating to care-recipient	Dementia	30	21.13 (6.17)	4.495 (47)	.0005
	Intellectual Disability	19	28.95 (5.52)		
Satisfactions relating to caregiver	Dementia	30	18.03 (9.16)	1.766 (47)	.084
	Intellectual Disability	19	22.89 (9.74)		
Satisfactions relating to interpersonal dynamic	Dementia	30	5.57 (3.00)	2.471 (47)	.017
	Intellectual Disability	19	7.79 (3.17)		

*one participant in the dementia group failed to complete the CASI therefore n=30

Table 3.3: Subscales of Satisfaction (CASI)

As caregiver ratings of severity of care-recipient difficulties were found to be significantly different between caregivers of individuals with dementia and caregivers of

individuals with intellectual disabilities it was deemed necessary to do an Analysis of Covariance (ANCOVA). However it should be noted that one of the assumptions of ANCOVA – the assumption of homogeneity of regression slopes – was violated. It has been found that, when group sizes are unequal and the homogeneity of regression slopes assumption has been violated then the ANCOVA may be severely affected (Field, 2005; DeShon & Alexander, 1996). D'Alonzo (2004) recommends that in order to address problems of heterogeneity of regression slopes the covariate variable (severity) is divided into a high and low category and then it is possible to perform a Two-Way ANOVA on the data. For the purposes of this analysis, severity was divided into low severity (0-5) and high severity (6-10). The results of the Two-Way ANOVA are shown below (Table 3.4) (Appendix 20). There was a non-significant main effect of severity on satisfaction ($F(1, 45)=.023$, $p=.879$, $w=.3$).

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	3805.337[a]	3	1268.446	4.820	.005
Intercept	94096.524	1	94096.524	357.544	.000
DIAG	2950.970	1	2950.970	11.213	.002
SEVCAT	6.166	1	6.166	.023	.879
DIAG * SEVCAT	1225.256	1	1225.256	4.656	.036
Error	11842.867	45	263.175		
Total	140762.000	49			
Corrected Total	15648.204	48			

[a] R Squared = .243 (Adjusted R Squared = .193)

Table 3.4: Impact of Severity on Satisfaction

This analysis also revealed another interesting finding. When caregiver satisfaction was plotted against care-recipient diagnosis and severity of care-recipient difficulties, it was found that greater caregiver satisfaction was reported in caregivers of individuals with

dementia when carers had rated care-recipient severity of difficulties to be high. Lower satisfaction was reported by caregivers of individuals with dementia when they had rated care-recipient difficulties as low (Appendix 20).

A retrospective power analysis was carried out in order to find out the power of this comparison (i.e. overall satisfaction between the two groups). The effect size between the caregiver groups was calculated using t and was found to be large (0.9) and the corresponding power of this analysis was found to be high (0.9). However before any firm conclusions are reached regarding differences in levels of satisfaction between caregivers of individuals with dementia and caregivers of individuals with intellectual disabilities, this study should be replicated.

3.4.2 **Hypothesis 2:** *It is hypothesized that caregiver burden will differ as a function of the type of caregiver; therefore it is predicted that caregivers of individuals with dementia will report greater burden than caregivers of individuals with an intellectual disability.*

Table 3.5 shows differences in mean burden scores for the two caregiver groups. Caregiver burden was not significantly different between caregivers of individuals with dementia and caregivers of individuals with intellectual disability ($t(48)=1.637$; $p=.108$) (Appendix 21).

	Care-recipient diagnosis	N*	Mean (S.D)	t (*df*)	p (2-tailed)
Caregiver Burden Interview	Dementia	31	29.45 (17.68)	1.637 (48)	.108
	Intellectual Disability	19	37.32 (14.30)		

Table 3.5: Caregiver Burden within Caregivers

Therefore it is not possible to reject the null hypothesis at this stage. Once again any effect of severity of difficulties was accounted for using ANCOVA (Appendix 22). This allowed caregiver burden to be examined whilst controlling for the effects of ratings of care-recipient difficulties. The assumptions for the ANCOVA were met and it was found that even when severity was controlled for, burden was not significantly different between the two groups of carers.

The effect size of this analysis was calculated post hoc using t to be 0.5 indicating this comparison had a medium effect size. In order to gain sufficient power to detect a medium effect size a total of 102 participants would need to be recruited. Given the limited power of this analysis, it would be necessary to replicate this study with a larger number of participants before any firm conclusions regarding caregiver burden can be drawn.

3.4.3 **Hypothesis 3:** *It is hypothesized that caregivers reported well-being will differ depending upon the satisfactions of caregivers; therefore it is expected that those caregivers who report greater well-being will also report greater levels of satisfaction and less burden with caregiving.*

In order to test this hypothesis a correlation matrix was performed on data relating to caregiver burden, caregiver satisfaction and caregiver well-being (Appendix 23). Table 3.6 shows the results of this analysis.

			Caregiver Burden Interview	Caregiver assessment of satisfaction index	Beck depression inventory	Beck anxiety inventory
Spearman's rho	Caregiver Burden Interview	Correlation Coefficient	1.000	.266	.506**	.472**
		Sig. (2-tailed)	.	.065	.000	.001
		N	50	49	46	46
	Caregiver assessment of satisfaction index	Correlation Coefficient	.266	1.000	.046	.139
		Sig. (2-tailed)	.065	.	.763	.361
		N	49	49	45	45
	Beck depression inventory	Correlation Coefficient	.506**	.046	1.000	.788**
		Sig. (2-tailed)	.000	.763	.	.000
		N	46	45	46	46
	Beck anxiety inventory	Correlation Coefficient	.472**	.139	.788**	1.000
		Sig. (2-tailed)	.001	.361	.000	.
		N	46	45	46	46

** Correlation is significant at the .01 level (2-tailed).

Table 3.6: Relationship between satisfaction, burden and well-being

Caregiver satisfaction was not significantly correlated with caregiver well-being. Neither caregiver's scores on the BAI or the BDI were related to caregiver satisfaction. However table 3.6 does show that there was a significant relationship between caregiver burden and caregiver well-being. Caregiver burden was significantly correlated with both

caregiver depression and caregiver anxiety. Although this does not indicate causality, it suggests an association between caregiver burden and caregiver well-being exists in this sample.

3.4.4 **Hypothesis 4:** *It is hypothesized that caregiver satisfaction will vary depending on the gender of the caregiver; therefore it is predicted that female caregivers will express less satisfaction than male caregivers.*

A Mann-Whitney Test was used to determine if caregiver gender influenced the levels of satisfaction reported (Appendix 24). In this sample of caregivers for individuals with dementia and individuals with intellectual disabilities, no difference was found based on gender (Table 3.7). Therefore there was no difference in reported levels of satisfaction between males and females in this sample. The null hypothesis cannot be rejected at this time. This finding may however be due to the extremely low number of male participants in this study (n=12).

	Participant Gender	N	Mean Rank	*U*	*p* (2-tailed)
Caregiver assessment of satisfaction index	Female	37*	26.04	183.50	.371
	Male	12	21.79		

*1 female participant failed to complete the CASI and so her data was not included in the analysis

Table 3.7: Differences in satisfaction depending on gender

The effect size of this test was calculated to be small (0.1). This indicates that a substantially larger group would be required before any potential differences in gender could be assessed more accurately.

3.4.5 Findings related to kin relationship and care-recipient difficulties

Although not included in the primary hypotheses, it was also of interest to find out about the effect of care-recipient difficulties on levels of burden and satisfaction. Differences in satisfaction and burden depending on kin relationship were also of interest and are considered below.

Table 3.8 shows that there were no differences between overall levels of memory and behaviour problems reported by caregivers (Appendix 25). To examine the effects of severity of care-recipient difficulties on these memory and behaviour ratings, an ANCOVA was performed. Assumptions of this test were upheld (Appendix 26) and it was found that even when severity was controlled for, care-recipient memory and behaviour problems did not differ significantly between the two groups of carers.

	Care-recipient diagnosis	N	Mean (S.D)	t (*df*)	p (2-tailed)
Memory and Behaviour Problems Checklist (Frequency)	Dementia	29*	34.72 (16.54)	.984 (46)	.330
	Intellectual Disability	19	30.32 (12.79)		

*2 participants failed to complete the MBPC and so they were not included in this analysis

Table 3.8: Care-recipients' memory and behaviour difficulties

As the Memory and Behaviour Problems Checklist (MBPC) asks caregivers to rate both the frequency of behaviours and their reaction to that behaviour for each of three subscales (depression, disruption and memory), it was also possible to examine whether the frequency of memory and behaviour difficulties was related to the amount of distress experienced within carers (Table 3.9 and Table 3.10) (Appendix 27 & 28). Both the

frequency of disruption ratings (t (46)=2.554, p=.014, 2 tailed) and the frequency of memory ratings (t (46)=3.653, p=.001, 2 tailed) were significantly different between the two groups of carers.

	Diagnosis of care-recipient	N	Mean (S.D)	t (*df*)	p (2-tailed)
Frequency of MBPC depression ratings	Dementia	29*	11.03 (8.10)	.746 (46)	.459
	Intellectual Disability	19	9.21 (8.55)		
Frequency of MBPC disruption ratings	Dementia	29*	5.97 (5.45)	2.554 (46)	.014
	Intellectual Disability	19	10.42 (6.60)		
Frequency of MBPC memory ratings	Dementia	29*	17.59 (7.16)	3.653 (46)	.001
	Intellectual Disability	19	10.68 (4.99)		

*2 participants failed to complete the MBPC-frequency scale and so they were not included in this analysis

Table 3.9: Memory and Behaviour problems – Frequency Ratings

Although memory difficulties were frequently reported in both groups of caregivers, carers of individuals with dementia reported higher mean distress with depressive behaviours, and carers of individuals with intellectual disability reported higher mean distress with both depressive and disruptive behaviours. Mean distress scores reported for memory related behaviours show that in both groups of caregivers, memory related behaviours caused the least amount of distress within caregivers (Table 3.10). However differences between distress reported for depressive behaviours, disruptive behaviours and memory behaviours were not significantly different between groups.

	Diagnosis of care-recipient	N	Mean Rank	Mann Whitney	p (2-tailed)
Frequency of MBPC depression ratings	Dementia	28*	23.36	248.000	.695
	Intellectual Disability	19	24.95		
Frequency of MBPC disruption ratings	Dementia	28*	20.89	179.000	.056
	Intellectual Disability	19	28.58		
Frequency of MBPC memory ratings	Dementia	28*	24.93	240.000	.571
	Intellectual Disability	19	22.63		

* 3 participants failed to complete the MBPC-reaction scale and so they were not included in this analysis

Table 3.10: Memory and Behaviour problems – Reaction Ratings

In order to investigate whether kin relationship affected caregiver burden or satisfaction a separate ANOVA was performed on each of the data sets and can be seen in Table 3.11 and Table 3.12. Kin relationship was split into four categories (parent, spouse, child and other) and satisfaction and burden scores were compared both between and within groups of caregivers.

			Sum of Squares	df	Mean Square	F	Sig.
Between Groups	(Combined)		3319.516	3	1106.505	4.039	.013
	Linear Term	Weighted	1422.810	1	1422.810	5.193	.027
		Deviation	1896.706	2	948.353	3.462	.040
	Quadratic Term	Weighted	278.384	1	278.384	1.016	.319
		Deviation	1618.322	1	1618.322	5.907	.019
Within Groups			12328.688	45	273.971		
Total			15648.204	48			

Table 3.11: Differences in Satisfaction depending on Kin Relationship

			Sum of Squares	df	Mean Square	F	Sig.
Between Groups	(Combined)		1109.465	3	369.822	1.342	.272
	Linear Term	Weighted	641.470	1	641.470	2.328	.134
		Deviation	467.995	2	233.998	.849	.434
	Quadratic Term	Weighted	465.932	1	465.932	1.691	.200
		Deviation	2.063	1	2.063	.007	.931
Within Groups			12672.855	46	275.497		
Total			13782.320	49			

Table 3.12: Differences in Burden depending on Kin Relationship

There was no significant effect of kin relationship on caregiver burden ($F(3, 46)=1.34$, $p>.05$, $\omega=.1$). However there was a significant effect of kin relationship on satisfaction

($F(3, 34)=4.04$, $p<.05$, $\omega=.4$). Post hoc comparisons (Appendix 29) show that there was a significant difference in caregiver satisfaction between parent carers and child carers.

3.5 Power Analysis

Once all participants had been recruited and included in the study, it was possible to calculate the power of the study using t. Using a large effect size (0.9), with alpha set at $p=0.05$, based on a total of 50 participants (19 in ID group and 31 in Dementia group) it was calculated that the power of the study was 0.9. Power of 0.8 or over would be required to be confident to achieve sufficient power to detect any effects which may have existed. As the power in this study was greater than 0.8, this suggests that the study had sufficient power to detect large effects in this sample.

3.6 Summary

A significant difference between caregiver groups in relation to satisfaction was found in this sample of caregivers. Satisfaction was found to be greater in carers of individuals with intellectual disabilities than in carers of individuals with dementia. It was found that satisfactions relating specifically to both the care-recipient and the interpersonal dynamic were significantly greater in caregivers of individuals with intellectual disabilities than in caregivers of individuals with dementia. Caregiver burden was not found to differ between caregivers of individuals with intellectual disabilities and caregivers of individuals with dementia in this sample. When looking at associations

between caregiver well-being and caregiver satisfaction, it was found that caregiver satisfaction was not correlated with caregiver well-being. However an association between caregiver burden and well-being was found. As correlations cannot predict causality, it is not possible to dictate the direction of this relationship. Further, no significant relationship was found between gender and caregiver satisfaction. Scores on a caregiver satisfaction measure were not significantly different between males and females. However the small number of male caregivers within this study may have affected this finding. The frequency with which care-recipient difficulties are noticed by caregivers was not significantly different between caregivers of individuals with dementia and caregivers of individuals with intellectual disabilities. Lastly, no significant effect of kin relationship was found for reported levels of burden, however there was a significant correlation between kin relationship and caregiver satisfaction.

CHAPTER 4: DISCUSSION

4.1 Overview

This section aims to highlight the results of this caregiver study and compare them to previous research in the area where it is available. Individual research hypotheses will be discussed in turn, outlining findings obtained from this study. Limitations of the study will be summarized, including those relating to the power of the study, the design and those pertaining to the sample and the measures used. Finally some clinical implications of the study will be introduced and ideas for future research will be postulated.

4.2 Discussion of Research Findings

4.2.1 Hypothesis One: *It is hypothesized that caregiver satisfaction will differ as a function of the type of caregiver; therefore it is predicted that caregivers of individuals with an intellectual disability will report greater satisfaction than caregivers of individuals with dementia.*

Caregiver satisfaction was found to be significantly different between the two groups of caregivers in this sample with carers of individuals with intellectual disabilities reporting significantly greater levels of satisfaction than carers of individuals with dementia (see Table 3.2). All caregivers in this study were able to identify at least one source of

satisfaction on the CASI. This is consistent with previous findings where high numbers of carers have described positive feelings about caregiving (Cohen *et al*, 2002; Andrén & Elmstähl, 2005).

It was not possible to statistically evaluate caregivers' answers on each of the 30 items of the CASI in this study. Due to the sheer number of comparisons this would involve, together with the small sample size this type of comparison was deemed inappropriate as it would be likely lead to Type 1 errors (Field, 2005). Future studies may wish to detect whether any discrepancies exist between the specific sources of satisfaction identified by carers of individuals with dementia and those reported by carers of individuals with intellectual disabilities. However when looking at satisfactions amongst Swedish caregivers Lundh (1999) found that the largest source of satisfaction for all groups of carers was being able to give something to the care-recipient that brought him or her happiness and pleasure. This was found to be dependent on prior relationship; for instance, three carers (2 per cent) in Lundh's study reported a poor prior relationship with the care-recipient and none of these carers found being able to give the care-recipient happiness or pleasure to be a source of satisfaction. Lundh (1999) also found that whilst carers of individuals with intellectual disorders identified obtaining satisfaction from seeing small improvements in the care-recipient's condition and helping them to reach their full potential, this was not the case for carers of individuals with dementia. Reports from caregivers in this research study confirmed Lundh's finding.

It was however possible to compare caregivers on the three subsections of the CASI. Significant differences were found between the two groups on sections looking at satisfactions relating to the care-recipient and satisfactions pertaining to the interpersonal dynamic i.e. shared satisfactions between the carer and the care-recipient (see Table 3.3). Nolan and Lundh (1999) assessed caregiver satisfaction amongst carers of individuals with dementia living in the UK and Sweden (Nolan & Lundh, 1999). Satisfactions relating to the care-recipient were more common than satisfactions relating to the caregiver themselves. Results from this thesis are consistent with this. However Nolan and Lundh's study did not compare differences in satisfactions between groups of carers of individuals with dementia and intellectual disabilities and so a direct comparison with the results of this study is not possible.

The finding of this study that caregivers of individuals with dementia report less satisfaction relating primarily to the care-recipient and the interpersonal dynamic may provide important foci for interventions. For example, it may be important to enhance caregiver satisfaction in this vulnerable group of carers in order to maintain caregiving relationships. The finding that caregivers report less satisfactions relating primarily to themselves as the primary caregiver may mean that improving self-efficacy or carers own self perceptions may impact positively upon the caregiving relationship and help carers to develop a greater sense of purpose and value (Nolan & Lundh, 1999). An inability to identify satisfactions within the caregiving relationship has been related to an increased risk of difficult and abusive caregiving relationships (Cohen *et al*, 2002) and as such may be an important factor to consider when assessing caregiving environments.

It should be borne in mind that differences in caregiver satisfaction may also be as a result of differences in kin relationship between the caregiver and the care-recipient. For example, Andrén and Elmstähl (2005) found that the more distant the relationship, the lower the satisfaction. This will be discussed in greater detail in section 4.2.5 when kin relationship will be examined.

There are a number of differences between this thesis and the studies by Lundh (1999) and Nolan and Lundh (1999) which make direct comparison difficult. Neither of these two studies directly compared caregivers of individuals with dementia and intellectual disabilities. These studies also sought to identify common sources of satisfactions across carer groups and as such did not compare total satisfaction scores on the CASI. The majority of published studies to date focus on caregiver burden, and fail to assess caregiver satisfaction; those that have looked at caregiver satisfaction have not directly compared this concept in caregivers of individuals with dementia and caregivers of individuals with intellectual disabilities.

4.2.2 Hypothesis Two: *It is hypothesized that caregiver burden will differ as a function of the type of caregiver; therefore it is predicted that caregivers of individuals with dementia will report greater burden than caregivers of individuals with an intellectual disability.*

Caregiver burden did not differ between the caregivers in this sample. Mean burden scores for both carers of individuals with dementia and carers of individuals with intellectual disabilities fell within the mild-moderate range and were equivalent between carers of individuals with dementia and carers of individuals with intellectual disabilities (see Table 3.5).

No apparent statistically significant difference in the level of burden experienced by caregivers of individuals with dementia and caregivers of individuals with intellectual disorders contradicts an earlier finding by Whittick (1988). Whittick (1988) concluded that familial caregivers of individuals with dementia had slightly higher levels of distress than either mothers caring for adults with intellectual disabilities or mothers caring for children with intellectual disabilities. A possible explanation for this inconsistency include Whittick's (1988) use of the GHQ-30 to assess distress, whereas in this study the CBI was used to assess burden and the BDI and BAI were used to assess well-being within carers. Although the GHQ-30 is a well established measure of psychological distress (Goldberg, 1978; Whittick, 1988), the CBI is specifically sensitive to caregiver burden as it was designed with this purpose in mind (Zarit *et al*, 1980). Therefore it may be that no difference was found in caregiver burden in this sample due to the fact a more sensitive measurement of burden specifically related to caregiving was used. In addition, the small number of carers for individuals with intellectual disabilities who opted to take part in the current study may mean that any true differences between these carer populations remain undetected. Possible reasons for this sampling bias, in addition to the consequences of any bias, will be discussed later on in this chapter (see Section 4.3).

The length of caregiving career within this sample of carers may also have a role to play in explaining the inconsistency between the findings of this thesis and of Whittick's 1988 study. Although carers of individuals with intellectual disabilities had been caring for significantly more years than carers of individuals with dementia, both groups had mean caregiving careers spanning greater than nine years. This is a considerable amount of time and may have meant that carers of individuals with dementia had time to come to terms with and adjust to their caregiving role, and consequently resulting in the finding that the two groups did not differ on measures of caregiver burden. Whittick (1988) did not measure length of caregiving career in her study and so it is not possible to determine whether a shorter caregiving career within dementia caregivers accounted for her finding that burden was greater in this group of caregivers. However Gallagher-Thompson and Steffen (1994) found that individuals who had been caring for longer benefited more from a cognitive-behavioural approach than those caregivers who had been caring for a shorter period of time. Therefore, rather than being able to adjust to their situation over the years, these caregivers required more assistance with caregiving as time progressed. This lends support to the idea that another factor perhaps accounted for the finding that caregiver burden did not differ between caregivers of individuals with dementia and caregivers of intellectual disabilities. Perhaps only those caregivers who were coping well with their caregiving duties opted to take part in this study, thereby explaining why no difference in burden was detected.

Over half of caregivers caring for individuals with dementia in this study were spousal caregivers and this is another possible reason for the discrepancy between the findings in this investigation and those of Whittick (1988) who only looked at child carers of parents with dementia. Perhaps by obtaining a larger sample of caregivers, it would be possible to split carers into different kin relationship groups, thereby allowing differences between spousal caregivers, child caregivers and parent caregivers to be examined more closely. Cohen *et al* (2002) found that when caregivers report more positive feelings with caregiving, they are less likely to report feelings of depression, burden or poor health. As all participants in this study reported at least some satisfactions with their caregiving role, this may also have contributed to the finding that burden was not found to differ between these two groups.

4.2.3 Hypothesis Three: *It is hypothesized that caregivers reported well-being will differ depending upon the satisfactions of caregivers; therefore it is expected that those caregivers who report greater well-being will also report greater levels of satisfaction and less burden with caregiving.*

Significant correlations were found between caregiver burden and caregiver well-being, whilst there was no significant correlation between caregiver satisfaction and caregiver well-being or between caregiver burden and caregiver satisfaction (see Table 3.6). Therefore within this study, burden and satisfaction were not dependent on one another; a caregiver could experience both burden and satisfaction at the same time. Concurringly López *et al* (2005) found no correlation between objective burden and caregiver

satisfaction. Although they did not use the CBI to measure burden, they did look at the length of caregiving career, the number of hours spent caring each day and the amount of external support provided as an indicator of burden and they too found that the amount of burden experienced by a caregiver was not dependent on the amount of satisfaction they had with their caregiving role.

In addition to the finding that caregiver satisfaction did not correlate with caregiver burden, it was also found that caregiver satisfaction did not correlate with caregiver well being in the sample reported here. Therefore caregiver reports of satisfaction were not found to be related to scores on measures of well-being. Although it would seem logical to suggest that caregiver well-being and satisfaction would be related, it would also seem appropriate to assume that caregiver satisfaction and burden would be related. As has already been shown however, caregiver burden and satisfaction have not been found to be significantly correlated with each other (López *et al*, 2005). Caregivers can experience both satisfaction and burden independently or in parallel. This may also be the case therefore for satisfaction and well-being; i.e. that caregivers' well-being is not dependent on the amount of satisfaction they receive from caregiving. This would suggest that other factors, besides caregiving, interact to lead to difficulties in well-being. Future research may wish to determine the extent to which factors such as other stressors (in the family or at work), or the amount of informal/formal support received by the caregiver are correlated with caregiver satisfaction.

A significant relationship was however found between caregiver burden and well-being, suggesting that difficulties within caregiving were related to the caregivers own mental health status. Although caregiver burden was highly correlated with levels of depression within caregivers, it can account for only 26 per cent of variation in caregiver well-being. Likewise, although caregiver burden was significantly correlated with caregiver anxiety, it can account for only 22 per cent of the variation in caregiver well-being. This leaves around three-quarters of the variability still to be accounted for by other variables (Field, 2005). Therefore the association between caregiver burden and well-being must be interpreted with caution. Shua-Haim *et al* (2001) also point out that in their sample of informal caregivers only 1 per cent of caregivers reported clinical depression. They concluded that this may represent an attempt by carers to under-report negative emotional symptoms in order that they can remain in their role as primary carer. As such, levels of depression or anxiety within caregivers may be underestimated. Given that correlations cannot suggest causality, and in order to rule out any third factor accounting for this association it would be necessary to compare caregiver burden and caregiver well-being directly in future samples of caregivers. This could be done using t-tests or ANOVAs. It was not felt appropriate to make these comparisons here, as they had not been specified *a priori*.

4.2.4 **Hypothesis Four:** *It is hypothesized that caregiver satisfaction will vary depending on the gender of the caregiver; therefore it is predicted that female caregivers will express less satisfaction than male caregivers.*

No differences in satisfaction were found based on caregiver gender. This finding is inconsistent with a number of published studies that have found that female caregivers experience greater distress than their male counterparts (Navaie-Waliser, 2002; Heller *et al*, 1997) and report fewer positives associated with caregiving than do male caregivers (Levesque *et al*, 1995). The lack of a gender difference in this study may be due to sampling biases. As only 24 per cent (n=12) of participants were male caregivers, it is likely that there were insufficient numbers to detect any real differences between the sexes. There is a need for more research using larger samples of male caregivers in order that the effects on both male and female caregivers can be evaluated.

It is also possible that differences were not found between the sexes because of the low level of burden (mild to moderate) found within this sample of caregivers (see Table 3.5). Differences may therefore become evident in those caregivers facing increased demands of caregiving. Gender differences in the previous research may also have been due to an effect of kin relationship between the caregiver and the care-recipient, rather than due to the gender of the caregiver. The lack of an effect of gender on caregiver satisfaction in this sample may be due to the fact that 63 per cent of participants were spousal or parental caregivers. Greater satisfaction has been found in caregivers with a closer kin relationship to the care-recipient (Andrén and Elmstähl, 2005). This will be discussed further in the following section (Section 4.2.5).

4.2.5 Findings related to kin relationship and care-recipient difficulties

4.2.5.1 Differences between satisfaction / burden and kin relationship

When caregiver burden and satisfaction were compared to kin relationship, no significant effect of kin relationship was found on caregiver burden. A significant relationship was found between kin relationship and caregiver satisfaction (Table 3.11). It has been argued that kin relationship can affect feelings of commitment and obligation and in turn how caregiving is experienced (Zarit & Edwards, 1996). Once again, a larger sample would be required before caregivers could be divided into different kin relationship categories for meaningful comparison on outcomes such as caregiver burden and satisfaction. Perhaps by carrying out a study which has a narrower focus, e.g. that specifically looks at spousal caregivers in comparison to parental caregivers, differences between different types of caregivers may be more evident.

Andrén and Elmstähl (2005) found that the more distant the relationship, the lower the satisfaction. Sixty-three per cent of carers in this study were close family members (e.g. spouse or parent) and it therefore may be that studies looking at satisfactions within a wider range of caregivers reach different conclusions regarding the effects of kin relationship on the level of caregiver satisfaction experienced.

4.2.5.2 Differences between satisfaction / burden and care-recipient difficulties

No significant effect of care-recipient difficulties was found on caregiver levels of satisfaction and burden in this sample of caregivers (Table 3.8-3.10). This supports

previous findings, which suggest that care-recipient difficulties do not affect caregiver outcome. For example Goode *et al* (1998) found that despite the progression of dementia, caregivers did not show worsening physical and mental health over time. Instead factors such as psychosocial resources i.e. appraisals, coping responses and social support were found to be more predictive of long term changes in caregiver mental and physical health. However, as previously noted, this finding assumes that caregivers provide an accurate assessment of family member's deficits, when in fact it is plausible that some caregivers either exaggerate or downplay the severity of these problems (Rymer *et al*, 2002).

4.3 Limitations

4.3.1 Statistical Power Analysis

The power of the study was calculated post hoc using t to be 0.9, meaning that there was a 90 per cent chance of detecting an effect if one genuinely existed (Field, 2005). Cohen (1992) has suggested that researchers should aim to achieve a power of 0.8 in order to obtain sufficient confidence in the power of their analyses. The adequate power of this study means that there is sufficient ability to detect any effects that may exist.

This study should however be replicated with a larger sample of caregivers for individuals with intellectual disabilities. Recruitment in this sample of caregivers proved difficult and possible reasons for this (outlined in Section 4.3.3) include factors such as parental caregivers not identifying themselves as caregivers per se, and the reliance on

busy health professionals within a Community Learning Disability Team in order to provide potential participants with written information about the study.

Given the relatively large number of associations examined, and the small sample size of this study there is an increased chance of Type 1 Error i.e. discovering a significant result when in fact none exists (Field, 2005). A Bonferroni correction was also applied when investigating differences in satisfaction and a significant effect was maintained.

4.3.2 Methodological Considerations

4.3.2.1 Cross-Sectional Design

This study looked at caregivers at only one point in their caregiving career. It is recognised that caregivers' experiences may change over time and that by assessing caregivers at more than one time point, as is done in longitudinal studies, may mean that other similarities or differences between caregiver groups may become evident.

4.3.2.2 Self Report Bias

Given the fact that self-report questionnaires were used in this design there is the potential for recall errors to influence the data collected. Caregivers recall may be affected by a number of factors including their own mood or a reluctance to admit to the presence of stressors. For example Kramer (1993) concluded that depressed caregivers may view the past more negatively and appraise their current situation more severely. This may lead to exaggerated recall of difficulties associated with caregiving. Self-report

questionnaires also rely on the willingness or ability of the carer to admit to the presence of negative emotional states (Gaugler *et al*, 2007). Carers may not feel able to admit to stressors for fear the care-recipient will be removed from their care and they may exaggerate the positives within their situation if they feel it is what they should be reporting. This therefore could have led to inflated levels of satisfaction being reported by caregivers within this sample and may have meant that burden was actually under estimated in this sample. Pinquart and Sörensen (2005) suggest more objective measures of caregiving experiences and well being are needed in order to obtain a more accurate assessment of these factors.

4.3.3 Recruitment

A very low response rate (estimated at 33 per cent) from both groups of caregivers, but especially from those carers of individuals with intellectual disabilities, may have biased these conclusions, and this will be discussed in greater detail in the following section. Possible reasons for large non-compliance may be related to the fact that parents of children with intellectual disabilities and spouses caring for individuals with dementia may not identify themselves as caregivers. For example in a study by Baikie (2002) spouse caregivers identified themselves primarily as a spouse or equally as a spouse and carer and this factor may go some way to explaining why the response rate for a study specifically looking at caregivers was so low. Likewise Robinson and Williams (2002) found that parents rarely saw themselves as carers.

Another potential explanation for the lack of response to this study may be due to the fact that individuals working within Learning Disability Services in a local NHS Trust were required to identify and then approach potential participants regarding this study. Perhaps the low response rate may have been down to these professionals not having time or forgetting to ask caregivers to take part in this study.

Response rate has been found to decrease with age (Kaldenberg *et al*, 1994) and may be partly explained by poorer health rates in this population. It may therefore be that older caregivers did not respond to requests to take part in this study. Borg and Hallberg (2006) suggest a response of 60 per cent is needed in order to avoid a response bias. As this study had an estimated response rate totalling around half this amount, this opens up the possibility that a response bias existed and results should therefore be interpreted with caution.

4.3.4 The Sample

This study exclusively examined informal caregivers of patients referred to psychiatric services, either within the dementia or learning disabilities services. As such these participants may be atypical of general community caregivers. Indeed, it is possible that care-recipients may have been referred to psychiatric services due to psychological distress within their caregivers. Those caregivers who continue to cope without becoming unwell may not come into contact with services and therefore would not have been approached regarding this study. Alternatively, it is also possible that those informal caregivers known to services are faced with caring for care-recipients with a

greater number of difficulties or with more severe difficulties; which also has the potential to influence appraisals of burden or satisfaction in addition to caregiver well-being.

The non-random selection of caregivers in this study may have led to a bias in recruitment and in turn to the data that was collected. Perhaps those caregivers who were experiencing more satisfactions with caregiving agreed to take part in the study. Or perhaps it was those caregivers with more support from family or external agencies (factors that have been found to influence caregiver satisfaction e.g. Gilhooly *et al*, 1984) who had time to take part in the study. These caregivers may have different caregiving experiences to those who had no time to participate in the study (McConaghy & Caltabiano, 2005).

All caregivers who participated in this study were Caucasian and therefore it is not possible to generalise conclusions to other racial groups. As prior education and socio-economic status were not measured it is not possible to determine whether this sample was representative of individuals who live within the local NHS Trust catchment area or the wider Scottish population.

Pahl and Quine (1987) found that carer stress varied depending on the diagnostic category of their child's intellectual disability. However, given the limited sample size and due to the fact that pre-morbid severity of difficulties was assessed, it was not felt

necessary to look at differences between diagnostic categories. Future studies may wish to take this on board though.

Due to the fact that caregivers were not compared with non-caregivers it is difficult to draw conclusions about how caregivers compare to spouses or parents or children within the general population on levels of burden, satisfaction and well-being.

Lastly, given the limited sample size, findings from this study should be interpreted with caution. A replication of the study with more caregivers needs to be completed before any firm conclusions can be drawn on specific differences between caregivers of individuals with dementia and intellectual disabilities.

4.3.5 Measures

Although the use of psychometric measures (like the CASI and the CBI) has allowed valuable research into caregiving and its impact on caregivers to take place, these measures have their limitations. For instance they cannot be used with non-caregivers and it is therefore not possible to determine caregiver burden in comparison to other groups such as single parents or individuals experiencing stressors at work (George & Gwyther, 1986). In addition, the reliance on summary scores for the comparison of individuals or individual groups has the potential to mask dimension specific patterns of caregiving (George & Gwyther, 1986). It is therefore useful to use measures of well-being with caregivers which can be compared to individuals in the general population and can assess specific aspects of well-being which are distinct from caregiving.

Repetition of this study with a further non-caregiver control group would allow for the comparison of caregivers and non-caregivers on dimensions of well-being.

A further limitation of the measures used in this study may be that they do not assess all aspects of a caregivers' experience, which is multi-dimensional by nature. For example, extraneous variables such as available resources, may confound experiences of burden or satisfaction but would remain undetected if using these measures only (López *et al*, 2005). The two caregiver groups assessed here were found to differ on factors such as length of caregiving and on subjective ratings of severity of care-recipient difficulties. It is possible that these factors may have influenced any differences observed between the groups. However, despite differences being detected in caregiver ratings of severity of care-recipient difficulties, no differences were found on the CBI or MBPC which when used together have been found to offer a complete view of caregiver difficulties and caregiver responses to such difficulties (Vitaliano *et al*, 1991).

Instruments such as the CBI assume that discomfort caused by certain caring tasks translate into feelings of burden (Nolan *et al*, 1990), however the occurrence of a problem does not necessarily imply distress in response to that experience. This may therefore affect the validity of this measure. However many items on the CBI are worded in such a way so that distress is inferred e.g. "Do you feel angry when you are around your relative?" (Vitaliano *et al*, 1991), and the CBI is a well-known and used tool within caregiver research.

The CASI was originally developed to study a range of caregivers and as such some items may not apply specifically to certain groups of caregivers. For example the items, "It's good to see small improvements in their condition" and "I am able to help the person I care for reach their full potential" were not seen as applicable by caregivers of individuals with dementia (Andrén & Elmstähl, 2005), however they were seen as appropriate for caregivers of individuals with intellectual disabilities (Lundh, 1999). Nolan *et al* (1998) also point out that the CASI has less utility as an overall satisfaction score and suggest it may be more useful in providing an individual profile of carers' experiences. However the authors of this measure also state that it can be used to find out about common satisfactions within a population of carers and to determine whether there is any variation within sub-groups of carers. With a larger sample it would be possible to look at the frequencies of carers identifying specific satisfactions within the CASI, however with a sample size of 50 this was deemed inappropriate.

4.4 Clinical Implications

The finding that all caregivers who participated in this research study could identify at least one satisfaction relating to caregiving suggests that clinicians should be routinely asking about the positive aspects of caring in order to gain a more accurate understanding of their experiences. As Cohen *et al* (2002) point out, asking caregivers about satisfactions experienced within caregiving can help to identify those caregivers who are more at risk of having poor outcomes, for example developing depression or institutionalising their relative. Therefore, the identification of satisfactions relating to

caring for someone with either dementia or intellectual disabilities can be important both for the caregiver themselves and for the care-recipient they are caring for.

As the number of individuals with dementia and with intellectual disabilities living in the population increases, so there is the potential for the number of their caregivers to likewise increase. Resources are needed to identify and support these caregivers. Learning how clinicians can help to decrease caregiver burden whilst at the same time enhancing caregiver satisfaction may lead to more successful intervention strategies in the long term (Andrén & Elmstähl, 2005; Veltman *et al*, 2002).

Information on the whole caregiver experience can help to inform interventions for caregivers such as the REACH (Resources for Enhancing Alzheimer's Caregiver Health) studies, which have compared specific interventions for caregivers. Cognitive-behavioural, psycho-educational approaches have been found to be superior to supportive interventions for female caregivers (Gallagher-Thompson *et al*, 2003). Within this same project Burns *et al* (2003) have also found that interventions focusing on both care-recipient behaviour and caregiver distress improve outcome more than interventions where the care-recipient is the sole focus.

By assessing a caregivers experience more thoroughly, taking account of burdens and satisfactions, resources may be allocated more effectively. For example, rather than practitioners assuming caregiving is burdensome, leading them perhaps at some point to recommend institutionalisation, they should also recognise the positives that can come

from caring and, instead, help caregivers to sustain their role where appropriate. This may in turn help to maintain caregiver well-being more than assisting caregivers to relinquish a role which continues to hold positive meaning for them (Motenko, 1989).

4.5 Future Research and General Conclusions

4.5.1 Recommendations for Future Research

Cross-sectional research is limited in determining directional effects and causality within caregiving. As such longitudinal studies are needed that examine caregiving experiences over time (Cohen *et al*, 2002). Evandrou *et al* (2002) found differences between cross-sectional and longitudinal data when assessing experiences of caregivers over the life course. They found multiple roles to be common over time, yet they were underestimated when investigated using a cross-sectional approach. Caregivers who participated in this study often reported that their answers to questionnaires would have varied if they had taken part in the study years or even months ago and this provide anecdotal evidence that caregivers experiences change over time.

In order to obtain a more accurate picture, future research should aim to assess care-recipients' views as well as caregivers when looking at caregiving relationships. Individuals with dementia and those with intellectual disabilities could provide information on their own experiences e.g. their mood or aspects of their quality of life (Gaugler *et al*, 2003).

Questions remain as to who is most likely to experience gain in caregiving (Kramer, 1997). Therefore, more research is required to investigate the effects of gender, age, kin relationship and race on the experience of gain within caregiving. In particular research with larger numbers of male caregivers is required to evaluate the effects of caregiving on males and females (Houde, 2002). Perhaps more detailed and accurate accounts of caregivers' experiences would be obtained using qualitative research methodologies as Veltman *et al* (2002) suggest.

It also would seem important to consider factors such as caregiver self-efficacy and feelings of reciprocity in future studies as these are both factors that have the potential to affect levels of burden and satisfaction within caregivers. Depp *et al* (2005) assessed self-efficacy based on kinship (daughters versus wives) and ethnicity (Hispanic/Latino versus Caucasian). They found lower self-efficacy amongst Caucasian and wife caregivers. Their study highlighted both the heterogeneity among caregivers in their experiences of caregiving and the importance of caregiver self-efficacy in determining caregiver outcome. Rabinowitz (2005) has found that caregiver self-efficacy predicted the risk of reduced health in a sample of caregivers of individuals with dementia. Self-efficacy has also been found to be important in caregivers of individuals with intellectual disabilities. Feldman *et al* (2007) found the degree of difficulties within the care-recipient to be related to caregiver self-efficacy. Given the significant difference in caregiver ratings in this thesis of care-recipient difficulties between caregivers of individuals with dementia and those of individuals with intellectual disabilities, it may

be interesting for future studies to determine the impact this has on caregiver self-efficacy.

Reciprocity has been found to be important in determining whether caregivers experience satisfaction in their caregiving role (Nolan and Lundh, 1999; Lundh, 1999). Despite cognitive difficulties within care-recipients, studies have shown that reciprocity is an important factor in Alzheimer's disease and those who care for individuals with this disorder (Graham & Bassett, 2006). Reid *et al* (2005) found reciprocity decreased caregiver burden and suggested that interventions based on fostering reciprocity were warranted. Therefore future studies may wish to look at reciprocity and its impact upon caregiver burden or caregiver satisfaction.

4.5.2 Conclusions

This study supports previous research (Andrén & Elmstähl, 2005; Lundh, 1999; Nolan *et al*, 1998), showing that family caregivers can experience both positive and negative reactions in caregiving. Burdens and satisfactions can co-exist and reflect different aspects of a carer's situation (Andrén & Elmstähl, 2005). Failing to pay adequate attention to the positive aspects of caregiving, can lead to skewed perceptions of caregiving experiences and can limit the ability of researchers and clinicians to enhance the theory of caregiver adaptation (Kramer, 1997). Given the potential benefits that have been found to be related to decreased caregiver burden and increased caregiver satisfaction, it is important that the rewards of caregiving be identified and supported for as long as possible (Heru & Ryan, 2006). The increased prevalence for dementia

(Dementia UK, 2007) and intellectual disabilities (McGrother *et al*, 2001) means that caregiving for these groups is set to remain a pertinent topic for future research.

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APPENDIX 1

LREC APPROVAL LETTER

Local Research Ethics Committee

Telephone:

Facsimile:

12 January 2007

Trainee Clinical Psychologist

Dear

Full title of study: **Caregiver Satisfaction: The positive and negative aspects of care giving for those caring for individuals with dementia and learning disabilities.**

REC reference number:

Thank you for your letter of , responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Application	5.2	01 November 2006
Investigator CV	1	01 November

		2006
Protocol	1	01 August 2006
Covering Letter	1	31 October 2006
Letter from Sponsor	1	20 October 2006
Interview Schedules/Topic Guides	1	30 October 2006
Questionnaire: QTN	1	01 January 1998
Participant Information Sheet: PIS	2	13 October 2006
Participant Consent Form: PCF	2	13 December 2006
Response to Request for Further Information		
Letter of Liability Insurances	1	28 July 2006
Supervisors CV	1	01 December 2005

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

SECRETARY TO THE GROUP

Enclosures:

Standard approval conditions [SL-AC1 for CTIMPs, SL-AC2 for other studies]
Site approval form

APPENDIX 2

PARTICIPANT CONSENT FORM

Centre Number::
Study Number:
Patient Identification Number for this trial:

CONSENT FORM

Title of Project: **Caregiver satisfaction: The positives and negatives of caring for someone with dementia or intellectual disabilities**

Name of Researcher: ----------

Please initial box

1. I confirm that I have read and understand the information sheet (dated 10.10.06, version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

When completed, 1 for participant; 1 for researcher site file

APPENDIX 3

PARTICIPANT INFORMATION SHEET

(DEMENTIA)

NHS

Participant Information Sheet

Caregiver Satisfaction: The positives and negatives of caring for someone with dementia or a learning disability.

I am a third year Clinical Psychology Trainee at the University of Edinburgh. As part of my Doctorate in Clinical Psychology I am undertaking research into different aspects of care giving.

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?
Much of the research undertaken with carers focuses on caregiver burden or the strain of caring. It is important however to consider the whole experience of care-giving, both positive and negative. This study aims to look at caregiver satisfaction within their caring role for individuals who are caring for someone with either dementia or a learning disability. It is the hope that by gaining greater awareness of all aspects of caring for someone, that more appropriate interventions or supports can be offered to caregivers.

The researcher ( ) is a Trainee Clinical Psychologist on the Edinburgh University Clinical Psychology Course. This will be submitted in part fulfilment of her Doctorate in Clinical Psychology.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care/future care you or your relative receives.

What will happen to me if I take part?
If you decide to take part in this study you will be asked to fill out 5 questionnaires, which should take you no longer than 50 minutes to complete. The questionnaires ask questions about caregiver burden, caregiver satisfaction, memory and behaviour problems of the individual receiving the care and also symptoms of anxiety and depression in the caregiver.

If a participant is unduly distressed, or discloses distress, then a referral to an appropriate organisation (e.g. GP, social work, psychology, psychiatry) may be sought. However this would only occur after discussion with the individual concerned.

If you decide to take part in this study a copy of your signed consent form will be kept on record until the end of the study. If you have any questions regarding this please contact (researcher) using the contact details below.

What are the possible disadvantages of taking part?
The questionnaires contain questions that some people may find difficult or upsetting to answer. However no harm will be caused by filling out these questionnaires. If any questions cause distress they do not have to be answered.

What are the possible advantages of taking part?
We cannot promise this study will help you, but the information we gain might help improve the support offered to caregivers of individuals with dementia or a learning disability in the future.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do her best to answer your questions ( ). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Will my taking part in the study be kept confidential?
All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your personal details removed from it so that you cannot be recognised from it. When this study is written up no individual's data will be identifiable.

Contact Details:
For further information about this study, or if you have any concerns please contact –
– ( )

What will happen to the results of the research study?
The results will be submitted in part fulfilment of the researcher's ( ) Doctorate in Clinical Psychology at Edinburgh University. It is also the intention of the researcher to look into publishing the results of this study in an academic journal once it has been completed.

Who has reviewed this study?
This study was given a favourable ethical opinion for conduct in the NHS by the Research and Ethics Committee.

Please keep this information sheet and one signed consent form if you decide to take part in this study.

Thank you for taking time to read this sheet and for considering taking part in this study.

APPENDIX 4

PARTICIPANT INFORMATION SHEET

(INTELLECTUAL DISABILITY)

NHS

Participant Information Sheet

Caregiver Satisfaction: The positives and negatives of caring for someone with dementia or a learning disability.

I am a third year Clinical Psychology Trainee at the University of Edinburgh. As part of my Doctorate in Clinical Psychology I am undertaking research into different aspects of care giving. This will be submitted in part fulfilment of her Doctorate in Clinical Psychology.

Because you care for someone with a learning disability, you are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of this study?
Much of the research undertaken with carers focuses on caregiver burden or the strain of caring. It is important however to consider the whole experience of care-giving, both positive and negative. This study aims to look at the satisfactions that caregivers like you experience when caring for someone a learning disability. It is the hope that by gaining greater awareness of all aspects of caring for someone, that more appropriate interventions or supports can be offered to caregivers.

As part of the study, I will be interviewing another group of carers – those who care for someone with dementia.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care/future care you or your relative receives.

What will happen to me if I take part?
If you decide to take part in this study you will be asked to fill out 5 questionnaires, which should take you no longer than 50 minutes in total to complete. The questionnaires ask questions about caregiver burden, caregiver satisfaction, memory and behaviour problems of the individual receiving the care and also symptoms of anxiety and depression in the caregiver.

If a participant is unduly distressed, or discloses distress, then a referral to an appropriate organisation (e.g. GP, social work, psychology, psychiatry) may be sought. However this would only occur after discussion with the individual concerned.

If you decide to take part in this study a copy of your signed consent form will be kept on record until the end of the study. If you have any questions regarding this please contact (researcher) using the contact details below.

What are the possible disadvantages of taking part?
The questionnaires contain questions that some people may find difficult or upsetting to answer. However no harm will be caused by filling out these questionnaires. If any questions cause distress they do not have to be answered.

What are the possible advantages of taking part?
We cannot promise this study will help you, but the information we gain might help improve the support offered to caregivers of individuals with dementia or a learning disability in the future.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do her best to answer your questions ( ). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Will my taking part in the study be kept confidential?
All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you that leaves the hospital will have your personal details removed from it so that you cannot be recognised from it. When this study is written up no individual's data will be identifiable.

Contact Details:
For further information about this study, or if you have any concerns please contact –
– ( )

What will happen to the results of the research study?
The results will be submitted in part fulfilment of the researcher's (Doctorate in Clinical Psychology at Edinburgh University. It is also the intention of the researcher to look into publishing the results of this study in an academic journal once it has been completed.

Who has reviewed this study?
This study was given a favourable ethical opinion for conduct in the NHS by the Research and Ethics Committee.

Please keep this information sheet and one signed consent form if you decide to take part in this study.

Thank you for taking time to read this sheet and for considering taking part in this study.

APPENDIX 5

PARTICIPANT OPT-IN FORM

NHS

CARE GIVER STUDY

I would (tick one of the following):

[ ] Like to participate in this study. Please contact me so that we can set up a meeting.

[ ] Like to learn more about your study before I decide to participate. Please contact me.

Name: _____

Address:

_____

_____

_____

_____

_____

Telephone Number, including area code

(_____) _____

Please return this form in the enclosed envelope. Or contact directly –

Tel: ( )

Postal Addr

E-Mail.

APPENDIX 6

DEMOGRAPHIC INFORMATION SCHEDULE

NHS

Caregiver Satisfaction – Information Schedule

This questionnaire is split up into questions about you, the caregiver, and questions about the person you care for (care recipient).

Questions about you, the caregiver:

1. What is your gender?

Male	☐	Female	☐

2. What is your date of birth? ___/___/_____

3. What is your relationship to the care recipient?

Spouse	☐	Friend	☐
Sibling	☐	Other	☐
Child			

If other please give details_____

4. What is your marital status?

Single	☐	Divorced	☐
Married	☐	Widowed	☐
Separated	☐	Co-habiting	☐
Other	☐		

If other please give details_____

5. Do you have an occupation outside of your care giving role?

Yes	☐	No	☐

If 'Yes' please state your job title _____

6. How long have you been a carer for?

6-12 months	☐	3-4 years	☐	6-7 years	☐
1-2 years	☐	4-5 years	☐	7-8 years	☐
2-3 years	☐	5-6 years	☐	other	☐

If other please give details_____

7. Below are some activities that carers are often involved in. Please tick the activities that you are involved in your care giving (i.e. the sorts of things you help the care recipient with).

toileting		visitor	
washing		companion	
dressing		handling finances	
household chores		supervisor	
transportation		other	

Please provide details of these activities in the space below: _____

_____

_____

_____

_____

8. Approximately, how often do family members visit the care recipient?

daily		once a month	
2-3 times a week		once a year	
once a week		other	

If other please give details_____

9. Do you receive any support from family / services to assist you in your care giving duties?

Yes		No	

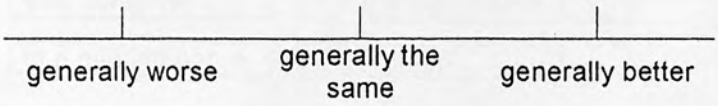
If 'Yes' please give details._____

_____

_____

10. Please rate the quality of the relationship you feel you had **in the past** with the care recipient. Please circle the number that applies to you.

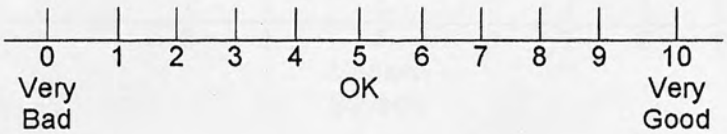
11. Please rate the quality of the relationship you feel you have **now** with the care recipient. Please circle the number that applies to you.



12. Approximately, how many hours do you spend caring for the care recipient each day?

0-2 hours	☐	12-14 hours	☐
3-5 hours	☐	15-17 hours	☐
6-8 hours	☐	18-20 hours	☐
9-11 hours	☐	21-24 hours	☐

13. Please rate how good you feel your own health is at the minute.



14. Do you have any other dependents in the house with you?

Yes	☐	No	☐

If 'Yes', how many dependents do you have? _____
If 'Yes', what are the ages of your dependents? _____
_____

Questions about the care recipient i.e. the person for whom you are a carer:

15. What is the care recipient's gender?

Male	☐	Female	☐

16. What is the care recipient's date of birth? ___/___/_____

17. What is the care recipient's marital status?

Single	☐	Divorced	☐
Married	☐	Widowed	☐
Separated	☐	Co-habiting	☐
Other	☐		

If other please give details_____

18. Where does the care recipient live?

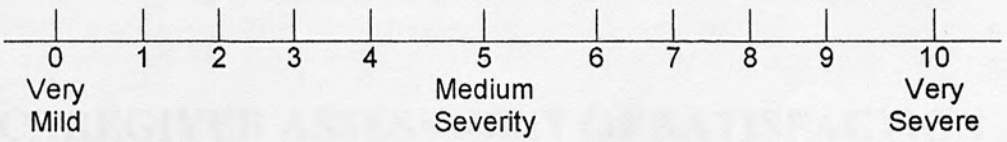
with caregiver	☐	in own home	☐
in a nursing home	☐	other	☐

19. Please state whether the care recipient has received a diagnosis of dementia or learning disability.

Yes	☐	No	☐
Other	☐		

If other please give details_____

20. Please rate the degree of severity of the care recipient's dementia or learning disability i.e. approximately how bad do you feel it is.



Thank you for answering this Information Schedule

APPENDIX 7

CAREGIVER ASSESSMENT OF SATISFACTION INDEX (CASI)

Carers' Assessment of Satisfactions Index (CASI)

CASI is a 30-item index and contains a series of statements which carers have made about the satisfactions they have experienced. Carefully read each statement and show if it applies by placing a tick in the space available. Together, responses can be used as the basis for discussing an agreed programme of support with the carer.

CARING CAN BE SATISFYING BECAUSE:	THIS APPLIES TO ME AND PROVIDES ME WITH: This does not apply to me	No real satisfaction	Quite a lot of satisfaction	A great deal of satisfaction
1 Caring has allowed me to develop new skills and abilities.				
2 The person I care for is appreciative of what I do.				
3 Caring has brought me closer to the person I care for.				
4 It's good to see small improvements in their condition.				
5 I am able to help the person I care for reach their full potential.				
6 I am able to repay their past acts of kindness.				
7 Caring provides a challenge.				
8 Despite all their problems the person I care for does not grumble or moan.				
9 It is nice to see the person I care for clean, comfortable and well turned out.				
10 Caring enables me to fulfil my sense of duty.				
11 I am the sort of person who enjoys helping people.				
12 I get pleasure from seeing the person I care for happy.				
13 It's good to help the person I care for overcome difficulties and problems.				
14 It's nice when something I do gives the person I care for pleasure.				
15 Knowing the person I care for the way I do, means I can give better care than anyone else.				
16 Caring has helped me to grow and develop as a person.				
17 It's nice to feel appreciated by those family and friends I value.				

Continued/...

CARING CAN BE SATISFYING BECAUSE:		THIS APPLIES TO ME AND PROVIDES ME WITH:			
		This does not apply to me	No real satisfaction	Quite a lot of satisfaction	A great deal of satisfaction
18	Caring has strengthened close family ties and relationships.				
19	It helps to stop me from feeling guilty.				
20	I am able to keep the person I care for out of an institution.				
21	I feel that if the situation were reversed, the person I care for would do the same for me.				
22	I am able to ensure that the person I care for has their needs tended to.				
23	Caring has given me the chance to widen my interests and contacts.				
24	Maintaining the dignity of the person I care for is important to me.				
25	I am able to test myself and overcome difficulties.				
26	Caring is one way of showing my faith.				
27	Caring has provided a purpose in my life that I did not have before.				
28	At the end of the day I know I will have done the best I could.				
29	Caring is one way of expressing my love for the person I care for.				
30	Caring makes me feel needed and wanted.				

Please add below any other aspects of caring that you find satisfying and indicate how much satisfaction they give you:

APPENDIX 8

CAREGIVER BURDEN INTERVIEW (CBI)

Caregiver Burden Assessment Scales	**Patient Name:** _____ **Rater Name:** _____ **Date:** _____

Instructions for caregiver: The questions above reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers.

Circle the response that best describes how you feel.	Never	Rarely	Sometimes	Quite Frequntl y	Nearly always
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid what the future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4

13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

APPENDIX 9

MEMORY & BEHAVIOUR PROBLEMS CHECKLIST (MBPC)

TERI, TRUAX, LOGSDON, UOMOTO, ZARIT, VITALIANO

Revised Memory and Behavior Problems Checklist

©L. Teri, Ph.D., RP-10, Department of Psychiatry and Behavioral Sciences, University of Washington Medical Center, Seattle, WA 98195

SUBJECT ID # _____ DATE _____/_____/_____
mm dd yy

PATIENT'S NAME _____
NAME OF PERSON FILLING OUT FORM

_____

INSTRUCTIONS

The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred during the past week. If so, how much has this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully.

FREQUENCY RATINGS:
0 = never occurred
1 = not in the past week
2 = 1 to 2 times in the past week
3 = 3 to 6 times in the past week
4 = daily or more often
9 = don't know/not applicable

REACTION RATINGS:
0 = not at all
1 = a little
2 = moderately
3 = very much
4 = extremely
9 = don't know/not applicable

Please answer all the questions below. Please circle a number from 0–9 for both *frequency* and *reaction*.

	Frequency	Reaction
1. Asking the same question over and over.	0 1 2 3 4 9	0 1 2 3 4 9
2. Trouble remembering recent events (e.g., items in the newspaper or on TV).	0 1 2 3 4 9	0 1 2 3 4 9
3. Trouble remembering significant past events.	0 1 2 3 4 9	0 1 2 3 4 9
4. Losing or misplacing things.	0 1 2 3 4 9	0 1 2 3 4 9
5. Forgetting what day it is.	0 1 2 3 4 9	0 1 2 3 4 9
6. Starting, but not finishing, things.	0 1 2 3 4 9	0 1 2 3 4 9
7. Difficulty concentrating on a task.	0 1 2 3 4 9	0 1 2 3 4 9
8. Destroying property.	0 1 2 3 4 9	0 1 2 3 4 9
9. Doing things that embarrass you.	0 1 2 3 4 9	0 1 2 3 4 9
10. Waking you or other family members up at night.	0 1 2 3 4 9	0 1 2 3 4 9
11. Talking loudly and rapidly.	0 1 2 3 4 9	0 1 2 3 4 9
12. Appears anxious or worried.	0 1 2 3 4 9	0 1 2 3 4 9
13. Engaging in behavior that is potentially dangerous to self or others.	0 1 2 3 4 9	0 1 2 3 4 9
14. Threats to hurt oneself.	0 1 2 3 4 9	0 1 2 3 4 9
15. Threats to hurt others.	0 1 2 3 4 9	0 1 2 3 4 9
16. Aggressive to others verbally.	0 1 2 3 4 9	0 1 2 3 4 9
17. Appears sad or depressed.	0 1 2 3 4 9	0 1 2 3 4 9
18. Expressing feelings of hopelessness or sadness about the future (e.g., "Nothing worthwhile ever happens," "I never do anything right").	0 1 2 3 4 9	0 1 2 3 4 9
19. Crying and tearfulness.	0 1 2 3 4 9	0 1 2 3 4 9

20. Commenting about death of self or others (e.g., "Life isn't worth living," "I'd be better off dead").	0 1 2 3 4 9	0 1 2 3 4 9
21. Talking about feeling lonely.	0 1 2 3 4 9	0 1 2 3 4 9
22. Comments about feeling worthless or being a burden to others.	0 1 2 3 4 9	0 1 2 3 4 9
23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life.	0 1 2 3 4 9	0 1 2 3 4 9
24. Arguing, irritability, and/or complaining.	0 1 2 3 4 9	0 1 2 3 4 9

APPENDIX 10

BECK DEPRESSION INVENTORY (BDI)

BDI®-II

Date:

me: _____ Marital Status: _____ Age: _____ Sex: _____

cupation: _____ Education: _____

structions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and n pick out the **one statement** in each group that best describes the way you have been feeling during the **past two eks, including today**. Circle the number beside the statement you have picked. If several statements in the group em to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one tement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness

0 I do not feel sad.
1 I feel sad much of the time.
2 I am sad all the time.
3 I am so sad or unhappy that I can't stand it.

2. Pessimism

0 I am not discouraged about my future.
1 I feel more discouraged about my future than I used to be.
2 I do not expect things to work out for me.
3 I feel my future is hopeless and will only get worse.

3. Past Failure

0 I do not feel like a failure.
1 I have failed more than I should have.
2 As I look back, I see a lot of failures.
3 I feel I am a total failure as a person.

4. Loss of Pleasure

0 I get as much pleasure as I ever did from the things I enjoy.
1 I don't enjoy things as much as I used to.
2 I get very little pleasure from the things I used to enjoy.
3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

0 I don't feel particularly guilty.
1 I feel guilty over many things I have done or should have done.
2 I feel quite guilty most of the time.
3 I feel guilty all of the time.

6. Punishment Feelings

0 I don't feel I am being punished.
1 I feel I may be punished.
2 I expect to be punished.
3 I feel I am being punished.

7. Self-Dislike

0 I feel the same about myself as ever.
1 I have lost confidence in myself.
2 I am disappointed in myself.
3 I dislike myself.

8. Self-Criticalness

0 I don't criticize or blame myself more than usual.
1 I am more critical of myself than I used to be.
2 I criticize myself for all of my faults.
3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

0 I don't have any thoughts of killing myself.
1 I have thoughts of killing myself, but I would not carry them out.
2 I would like to kill myself.
3 I would kill myself if I had the chance.

10. Crying

0 I don't cry anymore than I used to.
1 I cry more than I used to.
2 I cry over every little thing.
3 I feel like crying, but I can't.

_____ Subtotal Page 1

Continued on Back

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11. Agitation

0 I am no more restless or wound up than usual.

1 I feel more restless or wound up than usual.

2 I am so restless or agitated that it's hard to stay still.

3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0 I have not lost interest in other people or activities.

1 I am less interested in other people or things than before.

2 I have lost most of my interest in other people or things.

3 It's hard to get interested in anything.

13. Indecisiveness

0 I make decisions about as well as ever.

1 I find it more difficult to make decisions than usual.

2 I have much greater difficulty in making decisions than I used to.

3 I have trouble making any decisions.

14. Worthlessness

0 I do not feel I am worthless.

1 I don't consider myself as worthwhile and useful as I used to.

2 I feel more worthless as compared to other people.

3 I feel utterly worthless.

15. Loss of Energy

0 I have as much energy as ever.

1 I have less energy than I used to have.

2 I don't have enough energy to do very much.

3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

0 I have not experienced any change in my sleeping pattern.

1a I sleep somewhat more than usual.

1b I sleep somewhat less than usual.

2a I sleep a lot more than usual.

2b I sleep a lot less than usual.

3a I sleep most of the day.

3b I wake up 1–2 hours early and can't get back to sleep.

17. Irritability

0 I am no more irritable than usual.

1 I am more irritable than usual.

2 I am much more irritable than usual.

3 I am irritable all the time.

18. Changes in Appetite

0 I have not experienced any change in my appetite.

1a My appetite is somewhat less than usual.

1b My appetite is somewhat greater than usual.

2a My appetite is much less than before.

2b My appetite is much greater than usual.

3a I have no appetite at all.

3b I crave food all the time.

19. Concentration Difficulty

0 I can concentrate as well as ever.

1 I can't concentrate as well as usual.

2 It's hard to keep my mind on anything for very long.

3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

0 I am no more tired or fatigued than usual.

1 I get more tired or fatigued more easily than usual.

2 I am too tired or fatigued to do a lot of the things I used to do.

3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

0 I have not noticed any recent change in my interest in sex.

1 I am less interested in sex than I used to be.

2 I am much less interested in sex now.

3 I have lost interest in sex completely.

Subtotal Page 2

Subtotal Page 1

Total Score

APPENDIX 11

BECK ANXIETY INVENTORY

BAI®

E _____ DATE _____

is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by each om during the PAST WEEK, INCLUDING TODAY, by placing an X in the corresponding space in the column next to each symptom.

	NOT AT ALL	MILDLY It did not bother me much.	MODERATELY It was very unpleasant, but I could stand it.	SEVERELY I could barely stand it.
1. Numbness or tingling.				
2. Feeling hot.				
3. Wobbliness in legs.				
4. Unable to relax.				
5. Fear of the worst happening.				
6. Dizzy or lightheaded.				
7. Heart pounding or racing.				
8. Unsteady.				
9. Terrified.				
10. Nervous.				
11. Feelings of choking.				
12. Hands trembling.				
13. Shaky.				
14. Fear of losing control.				
15. Difficulty breathing.				
16. Fear of dying.				
17. Scared.				
18. Indigestion or discomfort in abdomen.				
19. Faint.				
20. Face flushed.				
21. Sweating (not due to heat).				

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APPENDIX 12

CAREGIVER CHARACTERISTICS

Caregiver Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Female	38	76.0	76.0	76.0
	Male	12	24.0	24.0	100.0
	Total	50	100.0	100.0	

Category of Caregiver Age

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	<65 years	38	76.0	76.0	76.0
	65 years or >	12	24.0	24.0	100.0
	Total	50	100.0	100.0	

Participant's relationship to Care-Recipient

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Spouse	16	32.0	32.0	32.0
	Child	12	24.0	24.0	56.0
	Parent	19	38.0	38.0	94.0
	Sibling	1	2.0	2.0	96.0
	Other	2	4.0	4.0	100.0
	Total	50	100.0	100.0	

Marital Status of Caregiver

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Married	44	88.0	88.0	88.0
	Not Married	6	12.0	12.0	100.0
	Total	50	100.0	100.0	

Hours spent caregiving - category

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	<9 hours	21	42.0	42.0	42.0
	>9 hours	29	58.0	58.0	100.0
	Total	50	100.0	100.0	

Length of Caregiving Category

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	<8 years	21	42.0	42.0	42.0
	>8 years	29	58.0	58.0	100.0
	Total	50	100.0	100.0	

Occupation outside of caregiving

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	28	56.0	56.0	56.0
	No	22	44.0	44.0	100.0
	Total	50	100.0	100.0	

Past relationship - category

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Poor or OK Relationship	11	22.0	22.0	22.0
	Good or Very Good Relationship	39	78.0	78.0	100.0
	Total	50	100.0	100.0	

Present Relationship - Category

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Same or Better	36	72.0	72.0	72.0
	Generally Worse	14	28.0	28.0	100.0
	Total	50	100.0	100.0	

Age Differences between Caregivers of Individuals with Dementia and Caregivers of Individuals with Intellectual Disabilities

Group Statistics

	Care-recipient diagnosis	N	Mean	Std. Deviation	Std. Error Mean
Participant Age (years)	dementia	31	57.48	11.272	2.025
	intellectual disability	19	52.26	10.418	2.390

Independent Samples Test

		Levene's tests for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	sig. (2-tailed)	mean difference	std. error difference	95% confidence interval of the difference	
									Lower	Upper
Participant Age (years)	Equal variances assumed	.393	.534	1.635	48	.109	5.22	3.193	-1.200	11.641
	Equal variances not assumed			1.667	40.566	.103	5.22	3.132	-1.107	11.549

Differences in Length of Caregiving Career between Caregivers of Individuals with Dementia and Caregivers of Individuals with Intellectual Disabilities

Group Statistics

	Care-recipient diagnosis	N	Mean	Std. Deviation	Std. Error Mean
Length of Caregiving Career (exact)	dementia	31	9.39	9.587	1.722
	intellectual disability	19	18.68	11.378	2.610

Independent Samples Test

		Levene's tests for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	sig. (2-tailed)	mean difference	std. error difference	95% confidence interval of the difference	
									Lower	Upper
Length of Caregiving Career (exact)	Equal variances assumed	.347	.559	-3.099	48	.003	-9.30	3.000	-15.328	-3.266
	Equal variances not assumed			-2.973	33.292	.005	-9.30	3.127	-15.657	-2.937

Differences in Caregiver Health Ratings between Caregivers of Individuals with Dementia and Caregivers of Individuals with Intellectual Disabilities

Group Statistics

	Care-recipient diagnosis	N	Mean	Std. Deviation	Std. Error Mean
Caregivers rating of own health (0-10)	dementia	31	6.06	2.943	.529
	intellectual disability	19	6.00	3.249	.745

Independent Samples Test

		Levene's tests for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	sig. (2-tailed)	mean difference	std. error difference	95% confidence interval of the difference	
									Lower	Upper
Caregivers ratings of own health (0-10)	Equal variances assumed	.606	.440	.072	48	.943	.06	.892	-1.729	1.858
	Equal variances not assumed			.071	35.302	.944	.06	.914	-1.790	1.919

APPENDIX 13

CARE-RECIPIENT CHARACTERISTICS

Care recipient's gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	female	27	54.0	54.0	54.0
	male	23	46.0	46.0	100.0
	Total	50	100.0	100.0	

Residency of care-recipient

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	with caregiver	26	52.0	52.0	52.0
	not with caregiver	24	48.0	48.0	100.0
	Total	50	100.0	100.0	

Marital status of care recipient

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	married	18	36.0	36.0	36.0
	single	32	64.0	64.0	100.0
	Total	50	100.0	100.0	

Differences in Care-recipient Ages

Group Statistics

	Care-recipient diagnosis	N	Mean	Std. Deviation	Std. Error Mean
Care recipient's age	dementia	31	71.06	13.186	2.368
	intellectual disability	19	20.26	10.370	2.379

Independent Samples Test

		Levene's tests for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	sig. (2-tailed)	mean difference	std. error difference	95% confidence interval of the difference	
									Lower	Upper
Care-recipient's age	Equal variances assumed	6.131	.017	14.285	48	.000	50.80	3.556	43.651	57.952
	Equal variances not assumed			15.134	44.897	.000	50.80	3.357	44.040	57.563

Differences in caregivers' ratings of care-recipient difficulties

Group Statistics

	Care-recipient diagnosis	N	Mean	Std. Deviation	Std. Error Mean
Severity of care-recipient's difficulties (0-10)	dementia	31	6.87	2.125	.382
	intellectual disability	19	5.42	1.865	.428

Independent Samples Test

		Levene's tests for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	sig. (2-tailed)	mean difference	std. error difference	95% confidence interval of the difference	
									Lower	Upper
Severity of Care-recipient's difficulties (0-10)	Equal variances assumed	.522	.474	2.449	48	.018	1.45	.592	.260	2.640
	Equal variances not assumed			2.529	42.059	.015	1.45	5.73	.293	2.607

APPENDIX 14

NORMALITY TESTS – SATISFACTION

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Caregiver assessment of satisfaction index	49	98.0%	1	2.0%	50	100.0%

Descriptives

			Statistic	Std. Error
Caregiver assessment of satisfaction index	Mean		50.53	2.579
	95% Confidence Interval for Mean	Lower Bound	45.34	
		Upper Bound	55.72	
	5% Trimmed Mean		50.60	
	Median		51.00	
	Variance		326.004	
	Std. Deviation		18.056	
	Minimum		16	
	Maximum		84	
	Range		68	
	Interquartile Range		29.50	
	Skewness		-.085	.340
	Kurtosis		-.915	.668

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Caregiver Assessment of Satisfaction Index	.084	49	.200*	.973	49	.328

* This is a lower bound of the true significance.

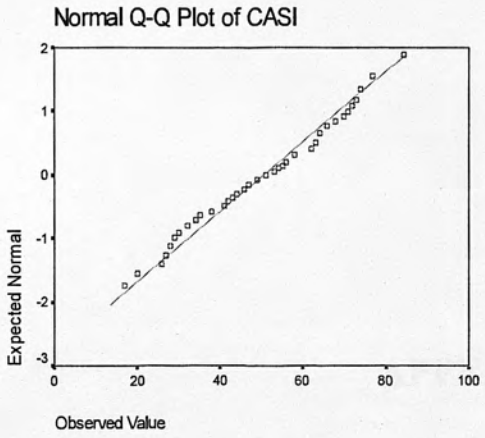
[a] Lilliefors Significance Correction

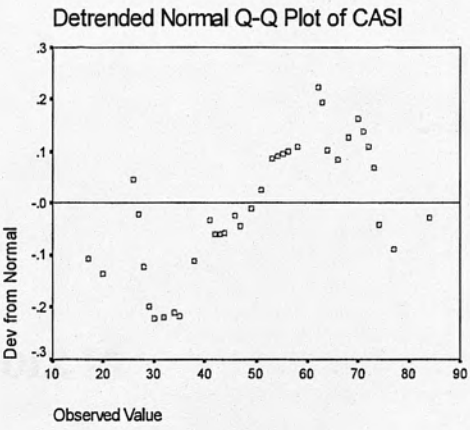
Caregiver assessment of satisfaction index Stem-and-Leaf Plot

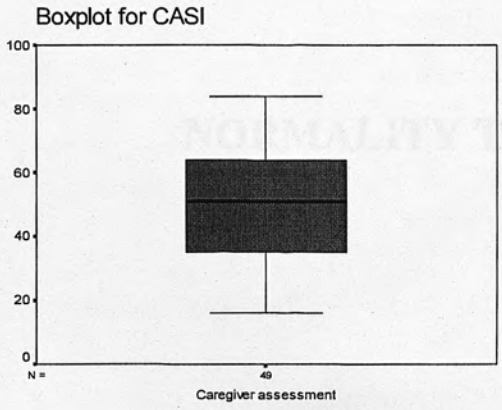
Frequency Stem & Leaf

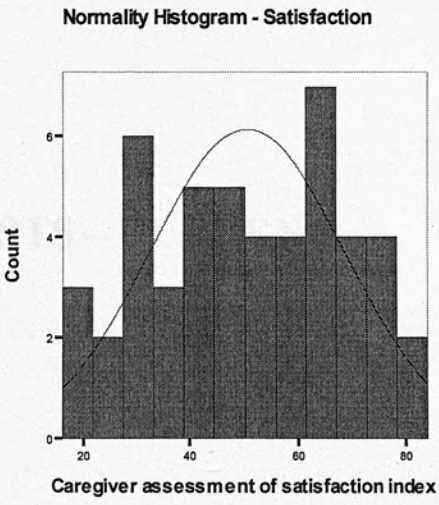
2.00 1 . 67
6.00 2 . 067889
6.00 3 . 022458
10.00 4 . 1123466799
8.00 5 . 13456888
8.00 6 . 23344468
7.00 7 . 0123447
2.00 8 . 44

Stem width: 10
Each leaf: 1 case(s)


Normal Q-Q Plot of CASI
Expected Normal
Observed Value


Detrended Normal Q-Q Plot of CASI
Dev from Normal
Observed Value


Boxplot for CASI
N =
49
Caregiver assessment


Normality Histogram - Satisfaction
Count
Caregiver assessment of satisfaction index

APPENDIX 15

NORMALITY TESTS – BURDEN

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Caregiver Burden Interview	50	100.0%	0	.0%	50	100.0%

Descriptives

			Statistic	Std. Error
Caregiver Burden Interview	Mean		32.44	2.372
	95% Confidence Interval for Mean	Lower Bound	27.67	
		Upper Bound	37.21	
	5% Trimmed Mean		32.13	
	Median		32.00	
	Variance		281.272	
	Std. Deviation		16.771	
	Minimum		1	
	Maximum		71	
	Range		70	
	Interquartile Range		23.50	
	Skewness		.373	.337
	Kurtosis		-.499	.662

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Caregiver Burden Interview	.113	50	.138	.968	50	.198

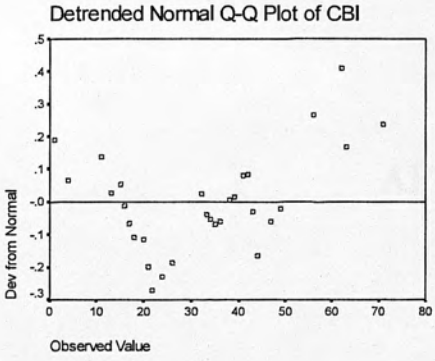
a Lilliefors Significance Correction

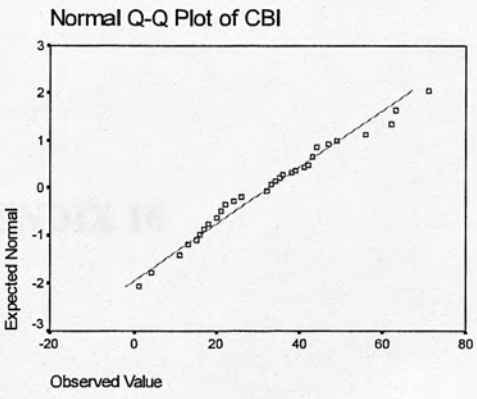
Caregiver Burden Interview Stem-and-Leaf Plot

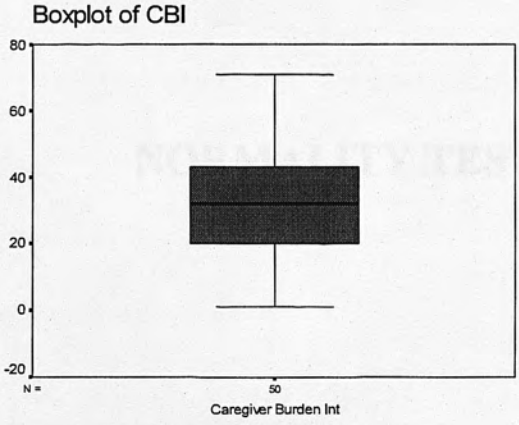
Frequency Stem & Leaf

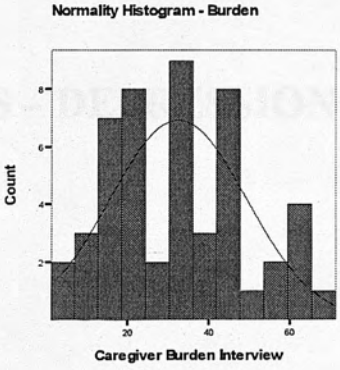
2.00 0 . 14
10.00 1 . 1113566788
10.00 2 . 0011122466
11.00 3 . 22223445689
10.00 4 . 1233333479
2.00 5 . 66
4.00 6 . 2233
1.00 7 . 1

Stem width: 10
Each leaf: 1 case(s)


Detrended Normal Q-Q Plot of CBI
Dev from Normal
Observed Value


Normal Q-Q Plot of CBI
Expected Normal
Observed Value


Boxplot of CBI
N =
Caregiver Burden Int


Normality Histogram - Burden
Count
Caregiver Burden Interview

APPENDIX 16

NORMALITY TESTS – DEPRESSION

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Beck Depression Inventory	46	92.0%	4	8.0%	50	100.0%

Descriptives

			Statistic	Std. Error
Beck Depression Inventory	Mean		14.13	1.732
	95% Confidence Interval for Mean	Lower Bound	10.64	
		Upper Bound	17.62	
	5% Trimmed Mean		13.24	
	Median		11.00	
	Variance		137.938	
	Std. Deviation		11.745	
	Minimum		0	
	Maximum		50	
	Range		50	
	Interquartile Range		17.25	
	Skewness		1.163	.350
	Kurtosis		.859	.688

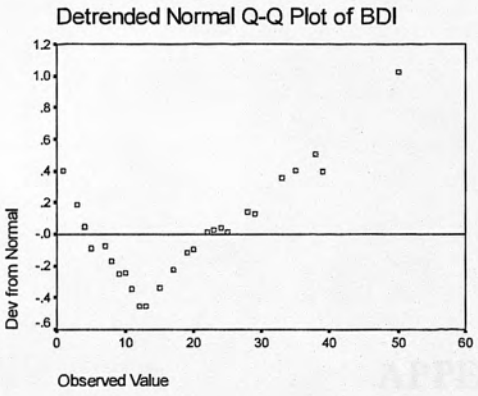
Tests of Normality

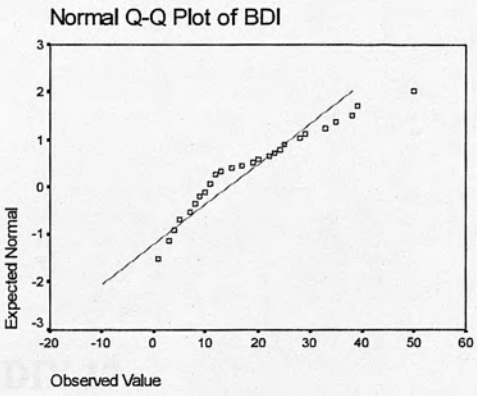
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Beck Depression Inventory	.202	46	.000	.888	46	.000

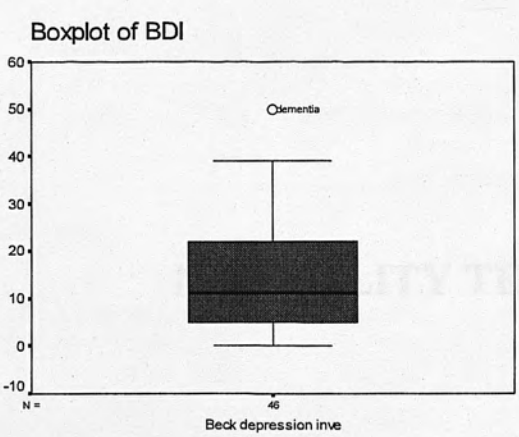
[a] Lilliefors Significance Correction

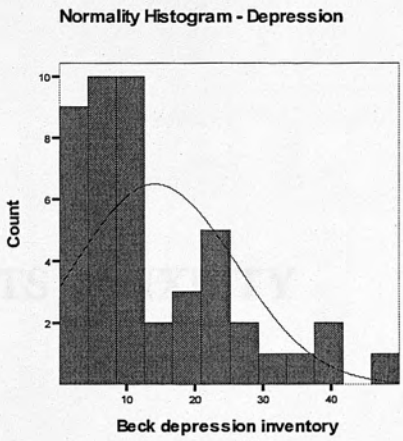
Beck depression inventory Stem-and-Leaf Plot

```
 Frequency    Stem &  Leaf

    9.00      0 .  011133344
   11.00      0 .  55557888889
   10.00      1 .  0011111223
    3.00      1 .  579
    4.00      2 .  0234
    4.00      2 .  5589
    1.00      3 .  3
    3.00      3 .  589
    1.00 Extremes    (>=50)

 Stem width:     10
 Each leaf:      1 case(s)
```


Detrended Normal Q-Q Plot of BDI
Dev from Normal
Observed Value


Normal Q-Q Plot of BDI
Expected Normal
Observed Value


Boxplot of BDI
dementia
N =
46
Beck depression inve


Normality Histogram - Depression
Count
Beck depression inventory

APPENDIX 17

NORMALITY TESTS – ANXIETY

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Beck Anxiety Inventory	46	92.0%	4	8.0%	50	100.0%

Descriptives

			Statistic	Std. Error
Beck Anxiety Inventory	Mean		14.13	2.077
	95% Confidence Interval for Mean	Lower Bound	9.95	
		Upper Bound	18.31	
	5% Trimmed Mean		13.27	
	Median		8.00	
	Variance		198.427	
	Std. Deviation		14.086	
	Minimum		0	
	Maximum		46	
	Range		46	
	Interquartile Range		27.00	
	Skewness		.773	.350
	Kurtosis		-.794	.688

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Beck Depression Inventory	.199	46	.000	.849	46	.000

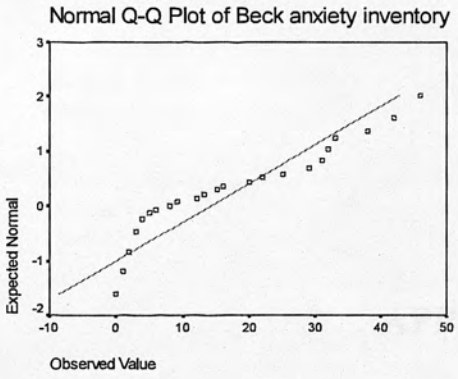
[a] Lilliefors Significance Correction

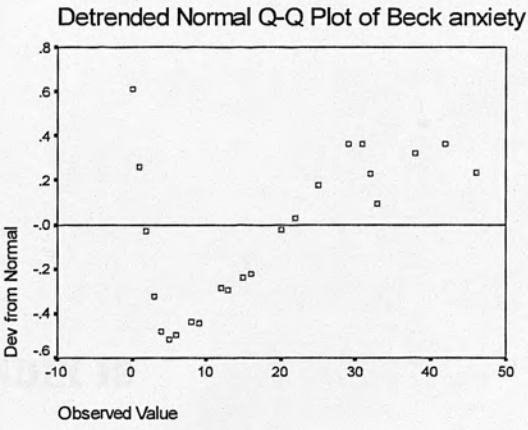
Beck anxiety inventory Stem-and-Leaf Plot

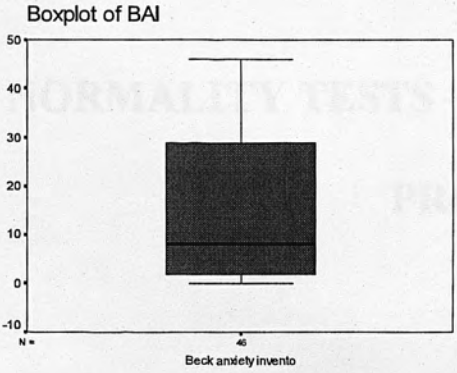
Frequency Stem & Leaf

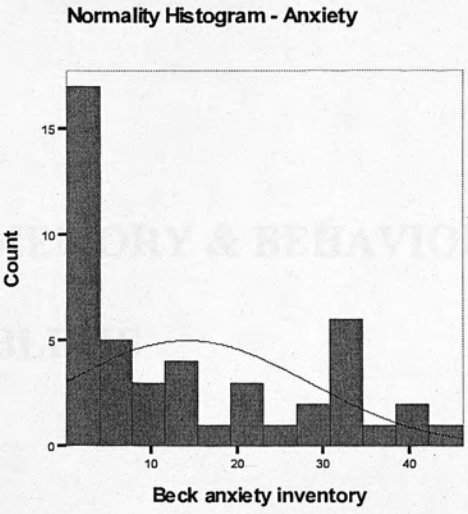
20.00 0 . 00001122222233333444
5.00 0 . 56889
3.00 1 . 233
2.00 1 . 56
3.00 2 . 002
3.00 2 . 599
6.00 3 . 112223
1.00 3 . 8
2.00 4 . 22
1.00 4 . 6

Stem width: 10
Each leaf: 1 case(s)


Normal Q-Q Plot of Beck anxiety inventory
Expected Normal
Observed Value


Detrended Normal Q-Q Plot of Beck anxiety
Dev from Normal
Observed Value


Boxplot of BAI
N =
Beck anxiety invento


Normality Histogram - Anxiety
Count
Beck anxiety inventory

APPENDIX 18

NORMALITY TESTS – MEMORY & BEHAVIOUR PROBLEMS

Case Processing Summary

	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Memory & Behaviour Problems Checklist	48	96.0%	2	40.0%	50	100.0%

Descriptives

			Statistic	Std. Error
	Mean		32.98	2.191
	95% Confidence Interval for Mean	Lower Bound	28.57	
		Upper Bound	37.39	
	5% Trimmed Mean		32.35	
	Median		33.00	
	Variance		230.361	
	Std. Deviation		15.178	
	Minimum		6	
	Maximum		72	
	Range		66	
	Interquartile Range		22.75	
	Skewness		.624	.343
	Kurtosis		.163	.674

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Memory & Behaviour Problems Checklist	.112	48	.179	.964	48	.152

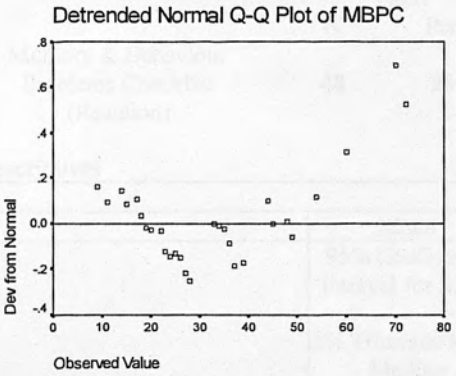
[a] Lilliefors Significance Correction

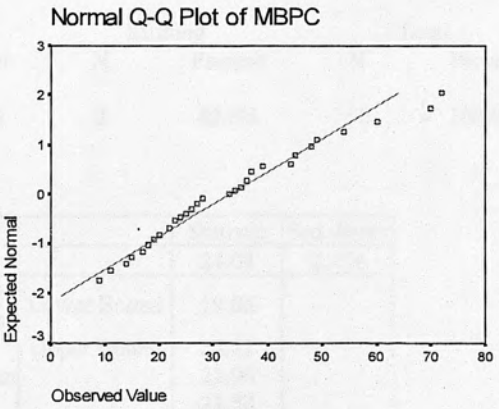
Memory and Behaviour Problems Checklist (Frequency) Stem-and-Leaf Plot

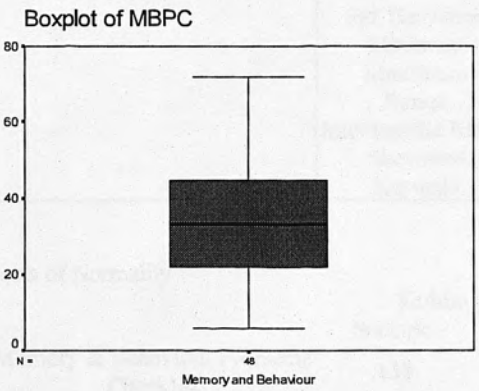
Frequency Stem & Leaf

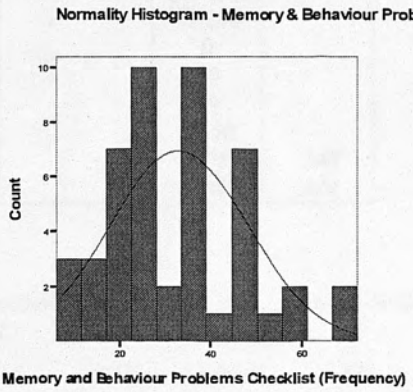
2.00 0 . 69
7.00 1 . 1457889
14.00 2 . 02223345667778
12.00 3 . 334556667779
8.00 4 . 45555899
1.00 5 . 4
2.00 6 . 00
2.00 7 . 02

Stem width: 10
Each leaf: 1 case(s)


Detrended Normal Q-Q Plot of MBPC
Dev from Normal
Observed Value


Normal Q-Q Plot of MBPC
Expected Normal
Observed Value


Boxplot of MBPC
N =
48
Memory and Behaviour


Normality Histogram - Memory & Behaviour Problems
Count
Memory and Behaviour Problems Checklist (Frequency)

Case Processing Summary

	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Memory & Behaviour Problems Checklist (Reaction)	48	96.0%	2	40.0%	50	100.0%

Descriptives

			Statistic	Std. Error
	Mean		24.08	2.496
	95% Confidence Interval for Mean	Lower Bound	19.06	
		Upper Bound	29.11	
	5% Trimmed Mean		22.96	
	Median		21.50	
	Variance		299.142	
	Std. Deviation		17.296	
	Minimum		0	
	Maximum		70	
	Range		70	
	Interquartile Range		25.50	
	Skewness		.775	.343
	Kurtosis		.247	.674

Tests of Normality

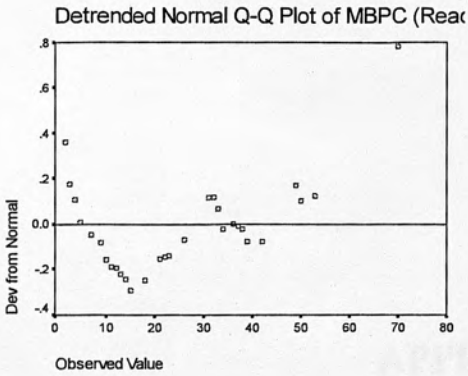
	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Memory & Behaviour Problems Checklist	.138	48	.023	.934	48	.009

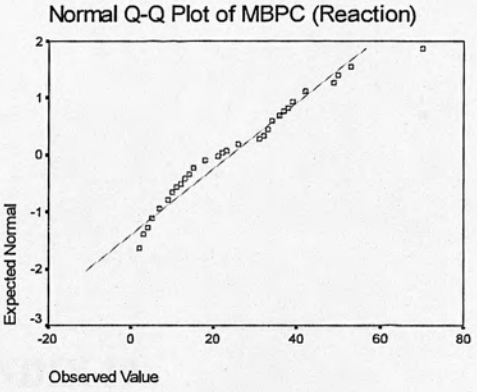
[a] Lilliefors Significance Correction

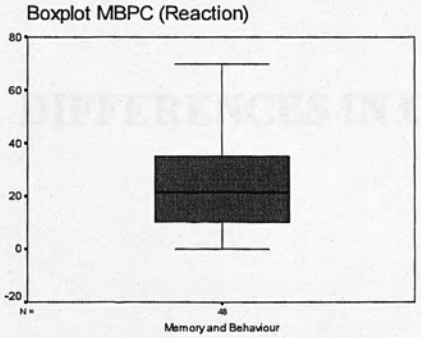
Memory and Behaviour Problems Checklist (Reaction) Stem-and-Leaf Plot

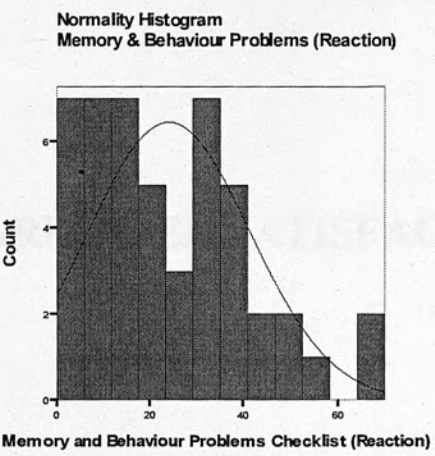
Frequency	Stem & Leaf
11.00	0 . 02234557799
12.00	1 . 001233455588
6.00	2 . 123666
12.00	3 . 123334467899
3.00	4 . 229
2.00	5 . 03
.00	6 .
2.00	7 . 00

Stem width: 10
Each leaf: 1 case(s)


Detrended Normal Q-Q Plot of MBPC (Reac
Dev from Normal
Observed Value


Normal Q-Q Plot of MBPC (Reaction)
Expected Normal
Observed Value


Boxplot MBPC (Reaction)
N =
48
Memory and Behaviour


Normality Histogram
Memory & Behaviour Problems (Reaction)
Count
Memory and Behaviour Problems Checklist (Reaction)

APPENDIX 19

DIFFERENCES IN CAREGIVER SATISFACTION

Differences in Caregiver Satisfaction

Group Statistics

	Care-recipient diagnosis	N	Mean	Std. Deviation	Std. Error Mean
Caregiver assessment of satisfaction index	dementia	30	44.77	16.720	3.053
	intellectual disability	19	59.63	16.617	3.812

Independent Samples Test

		Levene's tests for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	sig. (2-tailed)	mean difference	std. error difference	95% confidence interval of the difference	
									Lower	Upper
Caregiver assessment of satisfaction index	Equal variances assumed	.291	.592	-3.039	47	.004	-14.86	4.891	-24.704	-5.026
	Equal variances not assumed			-3.044	38.627	.004	-14.86	4.884	-24.747	-4.983

APPENDIX 20

DIFFERENCES IN SATISFACTION

(CONTROLLING FOR SEVERITY)

Between-Subjects Factors

		Value Label	N
Care-recipient diagnosis	1	dementia	30
	2	intellectual disability	19
Severity Category	1	Low severity	17
	2	High severity	32

Descriptive Statistics
Dependent Variable: Caregiver assessment of satisfaction index

Care-recipient diagnosis	Severity Category	Mean	Std. Deviation	N
dementia	Low severity	35.00	13.327	6
	High severity	47.21	16.816	24
	Total	44.77	16.720	30
intellectual disability	Low severity	64.09	16.991	11
	High severity	53.50	14.948	8
	Total	59.63	16.617	19
Total	Low severity	53.82	21.007	17
	High severity	48.78	16.368	32
	Total	50.53	18.056	49

Levene's Test of Equality of Error Variances[a]
Dependent Variable: Caregiver assessment of satisfaction index

F	df1	df2	Sig.
.501	3	45	.684

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.
[a] Design: Intercept+DIAG+SEVCAT+DIAG * SEVCAT

Tests of Between-Subjects Effects
Dependent Variable: Caregiver assessment of satisfaction index

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	3805.337[a]	3	1268.446	4.820	.005
Intercept	94096.524	1	94096.524	357.544	.000
DIAG	2950.970	1	2950.970	11.213	.002
SEVCAT	6.166	1	6.166	.023	.879
DIAG * SEVCAT	1225.256	1	1225.256	4.656	.036
Error	11842.867	45	263.175		
Total	140762.000	49			
Corrected Total	15648.204	48			

[a] R Squared = .243 (Adjusted R Squared = .193)

1. Care-recipient diagnosis
Dependent Variable: Caregiver assessment of satisfaction index

	Mean	Std. Error	95% Confidence Interval	
Care-recipient diagnosis			Lower Bound	Upper Bound
dementia	41.104	3.702	33.647	48.561
intellectual disability	58.795	3.769	51.204	66.387

2. Severity Category

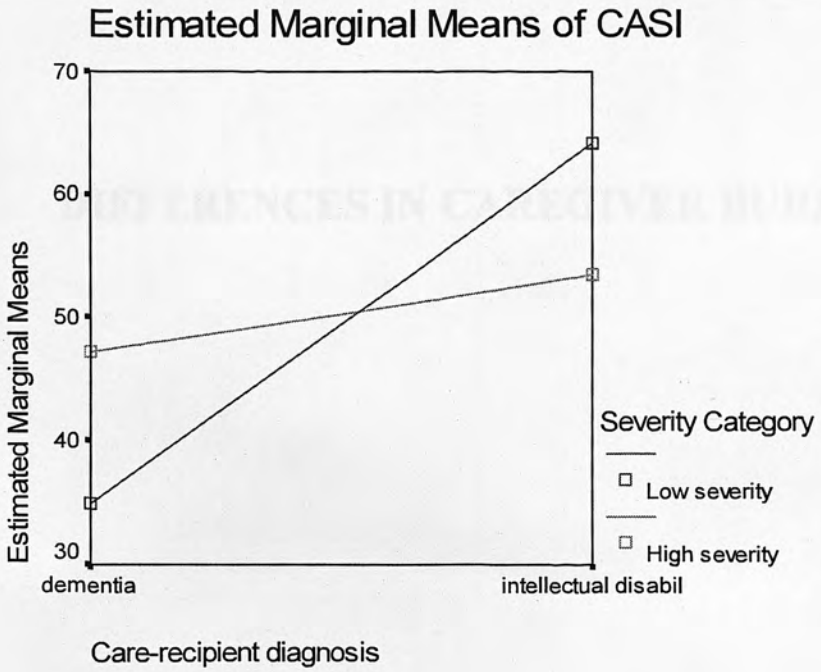
Dependent Variable: Caregiver assessment of satisfaction index

	Mean	Std. Error	95% Confidence Interval	
Severity Category			Lower Bound	Upper Bound
Low severity	49.545	4.117	41.254	57.837
High severity	50.354	3.311	43.685	57.024

3. Care-recipient diagnosis * Severity Category

Dependent Variable: Caregiver assessment of satisfaction index

		Mean	Std. Error	95% Confidence Interval	
Care-recipient diagnosis	Severity Category			Lower Bound	Upper Bound
dementia	Low severity	35.000	6.623	21.661	48.339
	High severity	47.208	3.311	40.539	53.878
intellectual disability	Low severity	64.091	4.891	54.239	73.943
	High severity	53.500	5.736	41.948	65.052



APPENDIX 21

DIFFERENCES IN CAREGIVER BURDEN

Differences in Caregiver Burden

Group Statistics

	Care-recipient diagnosis	N	Mean	Std. Deviation	Std. Error Mean
Caregiver Burden Interview	dementia	31	29.45	17.676	3.175
	intellectual disability	19	37.32	14.299	3.280

Independent Samples Test

		Levene's tests for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	sig. (2-tailed)	mean difference	std. error difference	95% confidence interval of the difference	
									Lower	Upper
Caregiver Burden Interview	Equal variances assumed	1.754	.192	-1.637	48	.108	-7.86	4.805	-17.525	1.797
	Equal variances not assumed			-1.723	44.230	.092	-7.86	4.565	-17.063	1.335

APPENDIX 22

DIFFERENCES IN BURDEN

(CONTROLLING FOR SEVERITY)

Between-Subjects Factors

		Value Label	N
Care-recipient diagnosis	1	dementia	31
	2	intellectual disability	19

Levene's Test of Equality of Error Variances[a]
Dependent Variable: Caregiver Burden Interview

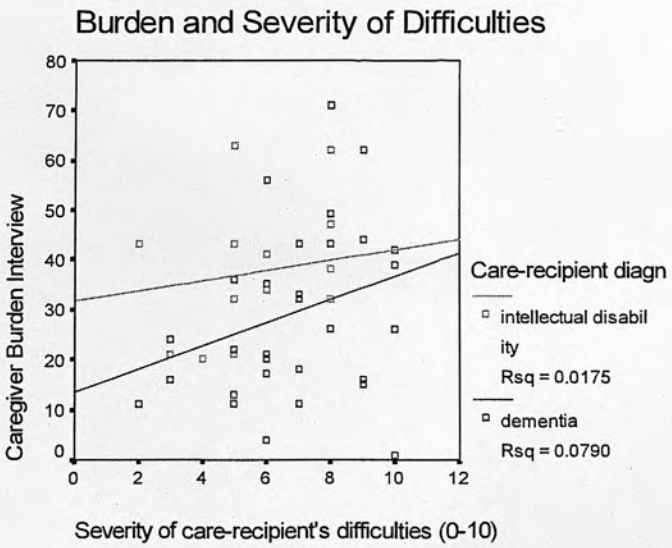
F	df1	df2	Sig.
.577	1	48	.451

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.
[a] Design: Intercept+DIAG+SEVERITY+DIAG * SEVERITY

Tests of Between-Subjects Effects
Dependent Variable: Caregiver Burden Interview

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	1533.664[a]	3	511.221	1.920	.140
Intercept	2264.284	1	2264.284	8.504	.005
DIAG	376.613	1	376.613	1.414	.240
SEVERITY	481.186	1	481.186	1.807	.185
DIAG * SEVERITY	75.183	1	75.183	.282	.598
Error	12248.656	46	266.275		
Total	66400.000	50			
Corrected Total	13782.320	49			

[a] R Squared = .111 (Adjusted R Squared = .053)



APPENDIX 23

CORRELATION MATRIX (BURDEN, SATISFACTION & WELL-BEING)

Correlations

			Caregiver Burden Interview	Caregiver assessment of satisfaction index	Beck depression inventory	Beck anxiety inventory
Spearman's rho	Caregiver Burden Interview	Correlation Coefficient	1.000	.266	.506	.472
		Sig. (2-tailed)	.	.065	.000	.001
		N	50	49	46	46
	Caregiver assessment of satisfaction index	Correlation Coefficient	.266	1.000	-.046	.139
		Sig. (2-tailed)	.065	.	.763	.361
		N	49	49	45	45
	Beck depression inventory	Correlation Coefficient	.506	-.046	1.000	.788
		Sig. (2-tailed)	.000	.763	.	.000
		N	46	45	46	46
	Beck anxiety inventory	Correlation Coefficient	.472	.139	.788	1.000
		Sig. (2-tailed)	.001	.361	.000	.
		N	46	45	46	46

** Correlation is significant at the .01 level (2-tailed).

APPENDIX 24

DIFFERENCES IN SATISFACTION DEPENDING ON GENDER

Descriptive Statistics

	N	Mean	Std. Deviation	Minimum	Maximum
Caregiver assessment of satisfaction index	49	50.53	18.056	16	84
Participant Gender	50	1.24	.431	1	2

Ranks

	Participant Gender	N	Mean Rank	Sum of Ranks
Caregiver assessment of satisfaction index	Female	37	26.04	963.50
	Male	12	21.79	261.50
	Total	49		

Test Statistics[a]

	Caregiver assessment of satisfaction index
Mann-Whitney U	183.500
Wilcoxon W	261.500
Z	-.895
Asymp. Sig. (2-tailed)	.371

[a] Grouping Variable: Participant Gender

APPENDIX 25

DIFFERENCES IN CARE-RECIPIENT DIFFICULTIES

Differences in Memory & Behaviour Problems

Group Statistics

	Care-recipient diagnosis	N	Mean	Std. Deviation	Std. Error Mean
Memory and Behaviour Problems Checklist (Frequency)	dementia	29	34.72	16.540	3.071
	intellectual disability	19	30.32	12.789	2.934

Independent Samples Test

		Levene's tests for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	sig. (2-tailed)	mean difference	std. error difference	95% confidence interval of the difference	
									Lower	Upper
Memory and Behaviour Problems Checklist (Frequency)	Equal variances assumed	.805	.374	.984	46	.330	4.41	4.481	-4.612	13.429
	Equal variances not assumed			1.038	44.620	.305	4.41	4.248	-4.149	12.965

APPENDIX 26

DIFFERENCES IN MEMORY & BEHAVIOUR PROBLEMS (CONTROLLING FOR SEVERITY)

Between-Subjects Factors

		Value Label	N
Care-recipient diagnosis	1	dementia	29
	2	intellectual disability	19

Descriptive Statistics
Dependent Variable: Memory and Behaviour Problems Checklist (Frequency)

Care-recipient diagnosis	Mean	Std. Deviation	N
dementia	34.72	16.540	29
intellectual disability	30.32	12.789	19
Total	32.98	15.178	48

Levene's Test of Equality of Error Variances[a]
Dependent Variable: Memory and Behaviour Problems Checklist (Frequency)

F	df1	df2	Sig.
.444	1	46	.508

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.
[a] Design: Intercept+DIAG+SEVERITY+DIAG * SEVERITY

Tests of Between-Subjects Effects
Dependent Variable: Memory and Behaviour Problems Checklist (Frequency)

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	458.230[a]	3	152.743	.648	.588
Intercept	3566.399	1	3566.399	15.134	.000
DIAG	41.640	1	41.640	.177	.676
SEVERITY	47.630	1	47.630	.202	.655
DIAG * SEVERITY	106.922	1	106.922	.454	.504
Error	10368.750	44	235.653		
Total	63033.000	48			
Corrected Total	10826.979	47			

[a] R Squared = .042 (Adjusted R Squared = -.023)

Parameter Estimates

Dependent Variable: Memory and Behaviour Problems Checklist (Frequency)

	B	Std. Error	t	Sig.	95% Confidence Interval	
Parameter					Lower Bound	Upper Bound
Intercept	31.746	11.089	2.863	.006	9.397	54.095
[DIAG=1]	-6.192	14.729	-.420	.676	-35.877	23.493
[DIAG=2]	0[a]	.	.	.	.	.
SEVERITY	-.264	1.940	-.136	.892	-4.173	3.645
[DIAG=1] * SEVERITY	1.587	2.356	.674	.504	-3.161	6.335
[DIAG=2] * SEVERITY	0	.	.	.	.	.

[a] This parameter is set to zero because it is redundant.

Contrast Results (K Matrix)

			Dependent Variable
Care-recipient diagnosis Simple Contrast[a]			Memory and Behaviour Problems Checklist (Frequency)
Level 1 vs. Level 2	Contrast Estimate		-6.192
	Hypothesized Value		0
	Difference (Estimate - Hypothesized)		-6.192
	Std. Error		14.729
	Sig.		.676
	95% Confidence Interval for Difference	Lower Bound	-35.877
		Upper Bound	23.493

[a] Reference category = 2

Test Results

Dependent Variable: Memory and Behaviour Problems Checklist (Frequency)

Source	Sum of Squares	df	Mean Square	F	Sig.
Contrast	41.640	1	41.640	.177	.676
Error	10368.750	44	235.653		

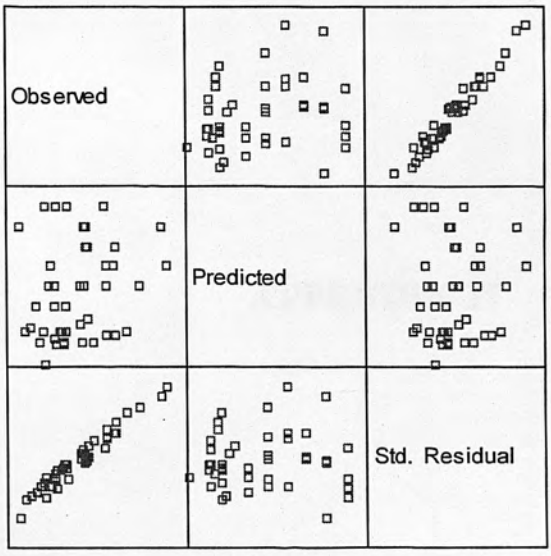
Care-recipient diagnosis

Dependent Variable: Memory and Behaviour Problems Checklist (Frequency)

	Mean	Std. Error	95% Confidence Interval	
Care-recipient diagnosis			Lower Bound	Upper Bound
dementia	33.933[a]	2.960	27.967	39.900
intellectual disability	30.075[a]	3.941	22.132	38.018

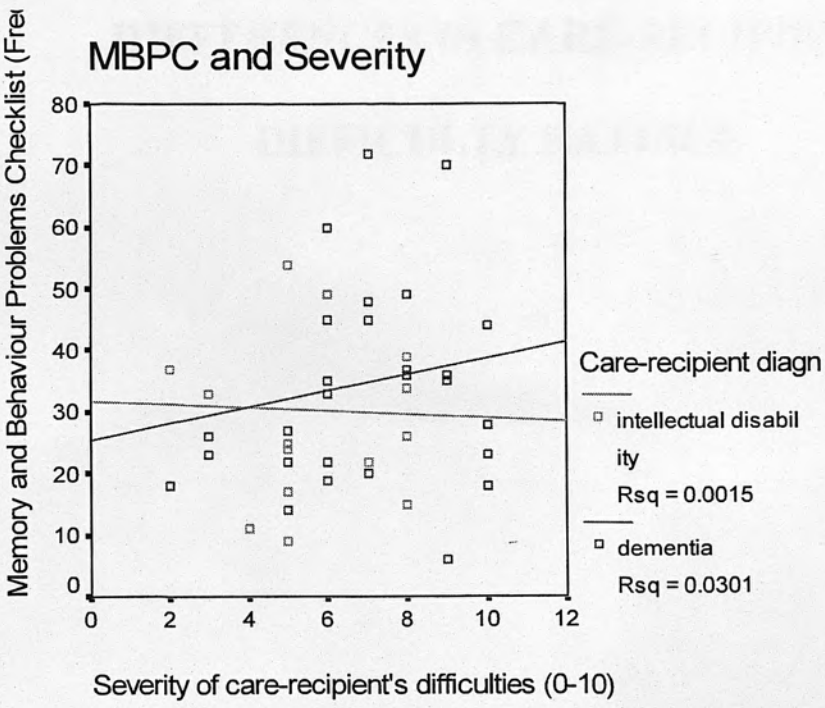
[a] Evaluated at covariates appeared in the model: Severity of care-recipient's difficulties (0-10) = 6.33.

Dependent Variable: MBPC



Model: Intercept + DIAG + SEVERITY + SEVERITY

MBPC and Severity



APPENDIX 27

DIFFERENCES IN CARE-RECIPIENT DIFFICULTY RATINGS

Differences in Care-recipient Difficulty Ratings

Group Statistics

	Diagnosis of care-recipient	N	Mean	Std. Deviation	Std. Error Mean
Frequency of MBPC depression ratings	Dementia	29	11.03	8.109	1.506
	Intellectual Disability	19	9.21	8.548	1.961
Frequency of MBPC disruption ratings	Dementia	29	5.97	5.448	1.012
	Intellectual Disability	19	10.42	6.569	1.507
Frequency of MBPC memory ratings	Dementia	29	17.59	7.164	1.330
	Intellectual Disability	19	10.68	4.989	1.145

Independent Samples Test

		Levene's tests for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	sig. (2-tailed)	mean difference	std. error difference	95% confidence interval of the difference	
									Lower	Upper
Frequency of MBPC depression ratings	Equal variances assumed	.003	.955	.746	46	.459	1.82	2.445	-3.097	6.745
	Equal variances not assumed			.738	37.175	.465	1.82	2.472	-3.185	6.833
Frequency of MBPC disruption ratings	Equal variances assumed	.975	.329	-2.554	46	.014	-4.46	1.745	-7.968	-.943
	Equal variances not assumed			-2.455	33.505	.019	-4.46	1.815	-8.146	-.765
Frequency of MBPC memory ratings	Equal variances assumed	1.780	.189	3.653	46	.001	6.90	1.889	3.099	10.705
	Equal variances not assumed			3.933	45.776	.000	6.90	1.755	3.369	10.435

APPENDIX 28

DIFFERENCES IN CARE-RECIPIENT DIFFICULTY REACTIONS

Differences in Care-recipient Reaction Ratings

Descriptive Statistics

	N	Mean	Std. Deviation	Minimum	Maximum
Reaction ratings - MBPC depression subscale	47	9.53	8.413	0	30
Reaction ratings - MBPC disruption subscale	47	8.09	8.500	0	28
Reaction ratings - MBPC memory subscale	47	6.64	6.236	0	28
Diagnosis of care-recipient	50	1.38	.490	1	2

Ranks

	Diagnosis of care-recipient	N	Mean Rank	Sum of Ranks
Reaction ratings - MBPC depression subscale	Dementia	28	23.36	654.00
	Intellectual Disability	19	24.95	474.00
	Total	47		
Reaction ratings - MBPC disruption subscale	Dementia	28	20.89	585.00
	Intellectual Disability	19	28.58	543.00
	Total	47		
Reaction ratings - MBPC memory subscale	Dementia	28	24.93	698.00
	Intellectual Disability	19	22.63	430.00
	Total	47		

Test Statistics[a]

	Reaction ratings - MBPC depression subscale	Reaction ratings - MBPC disruption subscale	Reaction ratings - MBPC memory subscale
Mann-Whitney U	248.000	179.000	240.000
Wilcoxon W	654.000	585.000	430.000
Z	-.392	-1.908	-.567
Asymp. Sig. (2-tailed)	.695	.056	.571

[a] Grouping Variable: Diagnosis of care-recipient

APPENDIX 29

DIFFERENCES IN SATISFACTION & BURDEN DEPENDING ON KIN RELATIONSHIP

SATISFACTION

Descriptives
Caregiver assessment of satisfaction index

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Spouse	15	45.73	16.381	4.230	36.66	54.81	16	74
Child	12	40.33	15.162	4.377	30.70	49.97	17	72
Parent	19	59.63	16.617	3.812	51.62	67.64	20	84
Other	3	57.67	23.159	13.371	.14	115.20	32	77
Total	49	50.53	18.056	2.579	45.34	55.72	16	84

Test of Homogeneity of Variances
Caregiver assessment of satisfaction index

Levene Statistic	df1	df2	Sig.
.260	3	45	.854

ANOVA
Caregiver assessment of satisfaction index

			Sum of Squares	df	Mean Square	F	Sig.
Between Groups	(Combined)		3319.516	3	1106.505	4.039	.013
	Linear Term	Weighted	1422.810	1	1422.810	5.193	.027
		Deviation	1896.706	2	948.353	3.462	.040
	Quadratic Term	Weighted	278.384	1	278.384	1.016	.319
		Deviation	1618.322	1	1618.322	5.907	.019
Within Groups			12328.688	45	273.971		
Total			15648.204	48			

Robust Tests of Equality of Means
Caregiver assessment of satisfaction index

	Statistic	df1	df2	Sig.
Welch	3.644	3	8.740	.059
Brown-Forsythe	3.216	3	7.980	.083

a Asymptotically F distributed.

Post Hoc Tests

Multiple Comparisons

Dependent Variable: Caregiver assessment of satisfaction index

			Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
	(I) Participant's relationship to Care-Recipient	(J) Participant's relationship to Care-Recipient				Lower Bound	Upper Bound
Tukey HSD	Spouse	Child	5.40	6.411	.834	-11.70	22.50
		Parent	-13.90	5.717	.086	-29.15	1.35
		Other	-11.93	10.468	.667	-39.86	15.99
	Child	Spouse	-5.40	6.411	.834	-22.50	11.70
		Parent	-19.30	6.103	.014	-35.58	-3.02
		Other	-17.33	10.684	.377	-45.84	11.17
	Parent	Spouse	13.90	5.717	.086	-1.35	29.15
		Child	19.30	6.103	.014	3.02	35.58
		Other	1.96	10.283	.997	-25.47	29.40
	Other	Spouse	11.93	10.468	.667	-15.99	39.86
		Child	17.33	10.684	.377	-11.17	45.84
		Parent	-1.96	10.283	.997	-29.40	25.47
Dunnett t (>control)	Spouse	Other	-11.93	10.468	.937	-32.64	
	Child	Other	-17.33	10.684	.978	-38.47	
	Parent	Other	1.96	10.283	.564	-18.38	

* The mean difference is significant at the .05 level.

a Dunnett t-tests treat one group as a control, and compare all other groups against it.

Homogeneous Subsets

Caregiver assessment of satisfaction index

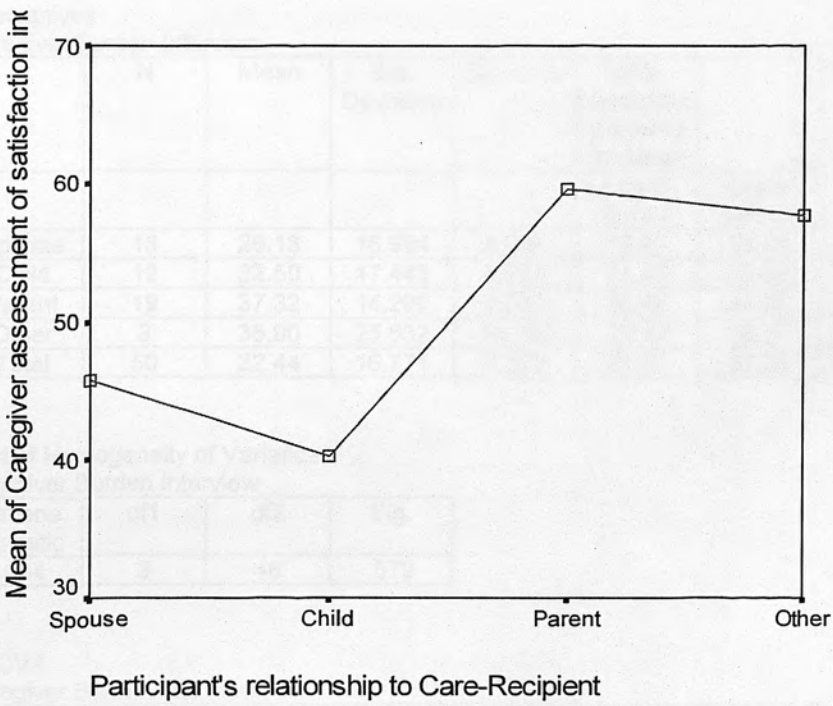
		N	Subset for alpha = .05	
	Participant's relationship to Care-Recipient		1	2
Tukey HSD	Child	12	40.33	
	Spouse	15	45.73	
	Other	3	57.67	
	Parent	19	59.63	
	Sig.		.125	
Ryan-Einot-Gabriel-Welsch Range	Child	12	40.33	
	Spouse	15	45.73	45.73
	Other	3	57.67	57.67
	Parent	19		59.63
	Sig.		.412	.066

Means for groups in homogeneous subsets are displayed.

a Uses Harmonic Mean Sample Size = 7.463.

b The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Means Plots


Mean of Caregiver assessment of satisfaction in
70
60
50
40
30
Spouse
Child
Parent
Other
Participant's relationship to Care-Recipient

BURDEN

Descriptives
Caregiver Burden Interview

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
Spouse	16	26.13	16.994	4.248	17.07	35.18	4	71
Child	12	32.50	17.443	5.035	21.42	43.58	1	56
Parent	19	37.32	14.299	3.280	30.42	44.21	18	63
Other	3	35.00	25.632	14.799	-28.67	98.67	11	62
Total	50	32.44	16.771	2.372	27.67	37.21	1	71

Test of Homogeneity of Variances
Caregiver Burden Interview

Levene Statistic	df1	df2	Sig.
.664	3	46	.579

ANOVA
Caregiver Burden Interview

			Sum of Squares	df	Mean Square	F	Sig.
Between Groups	(Combined)		1109.465	3	369.822	1.342	.272
	Linear Term	Weighted	641.470	1	641.470	2.328	.134
		Deviation	467.995	2	233.998	.849	.434
	Quadratic Term	Weighted	465.932	1	465.932	1.691	.200
		Deviation	2.063	1	2.063	.007	.931
Within Groups			12672.855	46	275.497		
Total			13782.320	49			

Robust Tests of Equality of Means
Caregiver Burden Interview

	Statistic	df1	df2	Sig.
Welch	1.263	3	8.582	.347
Brown-Forsythe	.947	3	6.901	.469

a Asymptotically F distributed.

Post Hoc Tests

Multiple Comparisons

Dependent Variable: Caregiver Burden Interview

			Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
	(I) Participant's relationship to Care-Recipient	(J) Participant's relationship to Care-Recipient				Lower Bound	Upper Bound
Tukey HSD	Spouse	Child	-6.38	6.339	.747	-23.27	10.52
		Parent	-11.19	5.632	.208	-26.20	3.82
		Other	-8.88	10.443	.830	-36.71	18.96
	Child	Spouse	6.38	6.339	.747	-10.52	23.27
		Parent	-4.82	6.120	.860	-21.13	11.50
		Other	-2.50	10.714	.995	-31.06	26.06
	Parent	Spouse	11.19	5.632	.208	-3.82	26.20
		Child	4.82	6.120	.860	-11.50	21.13
		Other	2.32	10.312	.996	-25.17	29.80
	Other	Spouse	8.88	10.443	.830	-18.96	36.71
		Child	2.50	10.714	.995	-26.06	31.06
		Parent	-2.32	10.312	.996	-29.80	25.17
Dunnett t (>control)	Spouse	Other	-8.88	10.443	.891	-29.50	
	Child	Other	-2.50	10.714	.725	-23.66	
	Parent	Other	2.32	10.312	.549	-18.05	

a Dunnett t-tests treat one group as a control, and compare all other groups against it.

Homogeneous Subsets

Caregiver Burden Interview

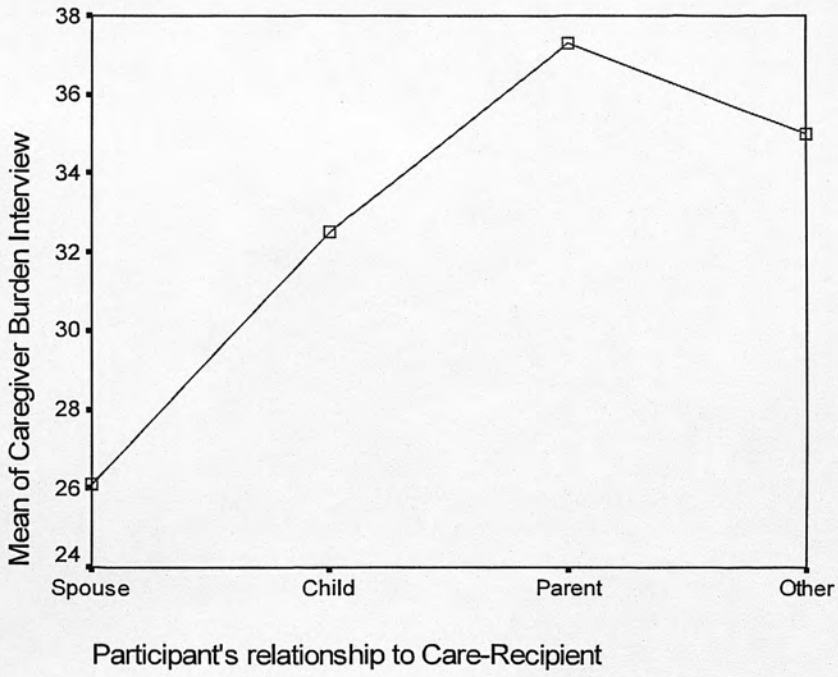
		N	Subset for alpha = .05
	Participant's relationship to Care-Recipient		1
Tukey HSD	Spouse	16	26.13
	Child	12	32.50
	Other	3	35.00
	Parent	19	37.32
	Sig.		.563
Ryan-Einot-Gabriel-Welsch Range	Spouse	16	26.13
	Child	12	32.50
	Other	3	35.00
	Parent	19	37.32
	Sig.		.239

Means for groups in homogeneous subsets are displayed.

a Uses Harmonic Mean Sample Size = 7.522.

b The group sizes are unequal. The harmonic mean of the group sizes is used. Type I error levels are not guaranteed.

Means Plots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36
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Mean of Caregiver Burden Interview
Spouse
Child
Parent
Other
Participant's relationship to Care-Recipient